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ABSTRACT

This manual is intended for young people with spinal cord injuries who are receiving rehabilitation services within the Spinal Cord Injury Unit at Shriners Hospital (San Francisco, California). An introduction describes the rehabilitation program, which includes family conferences, an individualized program, an independent living program, discharge to a special transition apartment, return to the community, and periodic reevaluation and ongoing training. Other introductory information covers diagnostic tests, the daily schedule, the therapy schedule, Unit policies, activity attendance rules, and the patient's rights and responsibilities. Later chapters present information on: (1) the nervous system and spinal cord injury; (2) skin care; (3) bladder care; (4) bowel care; (5) nutrition; (6) the respiratory system and care; (7) circulation; (8) complications of spinal cord injury; (9) medications; (10) physical therapy; (11) occupational therapy; (12) recreation therapy; (13) social services; (14) attendant care; (15) sexuality; and (16) equipment maintenance. A glossary is also provided. (DB)

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SHRINERS HOSPITAL
SPINAL CORD INJURY

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MANUAL

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TABLE OF CONTENTS

CHAPTER 1 • INTRODUCTION
CHAPTER 2 • THE NERVOUS SYSTEM AND SPINAL CORD INJURY
CHAPTER 3 • SKIN CARE
CHAPTER 4 • BLADDER CARE
CHAPTER 5 • BOWEL CARE
CHAPTER 6 • NUTRITION
CHAPTER 7 • THE RESPIRATORY SYSTEM
CHAPTER 8 • CIRCULATION
CHAPTER 9 • COMPLICATIONS
CHAPTER 10 • MEDICATIONS
CHAPTER 11 • PHYSICAL THERAPY
CHAPTER 12 • OCCUPATIONAL THERAPY
CHAPTER 13 • RECREATION THERAPY
CHAPTER 14 • SOCIAL SERVICES
CHAPTER 15 • ATTENDANT CARE
CHAPTER 16 • SEXUALITY
CHAPTER 17 • EQUIPMENT MAINTENANCE
INDEX AND GLOSSARY

WELCOME TO THE SPINAL CORD INJURY UNIT

The Spinal Cord Injury Unit (SCIU) at Shriners Hospital was opened to serve the special needs of spinal cord injured young people. In an atmosphere of support and hope, you and your family will learn to maintain your health, to be as independent as possible, and to find the resources you need in the community.

We have seen many people enjoy satisfying and productive lives after a spinal cord injury. Making the adjustment is hard work, but it can be done. In this book, along with information about your physical care, you will read about a few of our former patients who have agreed to share their stories and thoughts with you. We hope their advice and encouragement will be helpful to you.

Eric Rodriguez

Eric sustained a T-7 incomplete spinal cord injury in an auto accident and went through rehabilitation at Shriners.

Eric's advice to new patients: "Life will be fun again!! Live life fully, one day at a time. Do as many things as you can in one day."

Eric certainly takes his own advice! In addition to maintaining a full school schedule, Eric manages a football team, has a girlfriend, and has learned how to drive using hand controls. Next year he plans on college, with a major in computers. "Oh, and I have a job evenings and weekends, in an electronics firm."

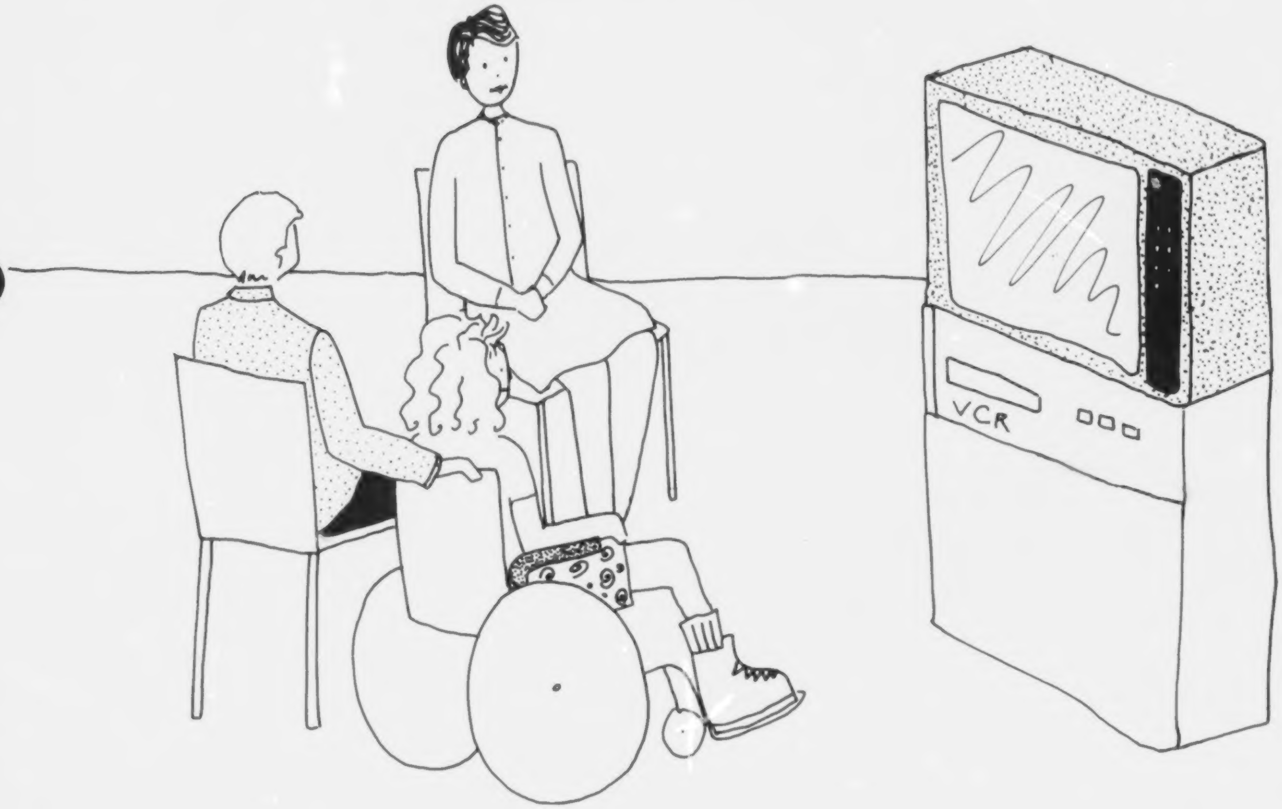
HOW TO USE THIS BOOK

This manual contains a great deal of information on every aspect of your care. It will serve as a workbook while you are in the hospital and a reference manual when you go home. We suggest you read this introductory chapter as soon as possible, so that you know how our program works. Chapter Two will give you some basic facts about the nervous system and about spinal cord injuries. The other chapters will help you learn how to take care of yourself, and to teach others to help you if necessary. Your nurses and therapists will guide your study of these topics, and provide other learning materials to meet your specific needs.

Before you go home, you will be expected to show that you have the knowledge and skills you need to stay healthy and be as independent as possible. If there is anything you do not understand, ask someone, or look it up in the manual, and get your questions answered. We want you to leave the hospital well-informed and ready to manage successfully at home.

OTHER LEARNING AIDS

The staff of the SCI Unit has produced a "Home-Care Video" which covers several important aspects of your care. You are encouraged to watch it at least once while you are in the hospital, and to take it home as a convenient demonstration tape for you and your caretakers. We also have an extensive library of books and other materials on many facets of rehabilitation and spinal cord injury. Please ask a nurse if you would like access to the library. Finally, remember your ever-present source of information and helpful hints, the SCI staff. We are here for you -- use us!!!



THE SCI REHABILITATION PROGRAM

WHAT IS REHABILITATION?

"REHABILITATION" means "restoring ability." The overall goal of the rehabilitation program is to enable you to maintain your health and to be as independent as possible once you leave the hospital. Because of your injury, you may need to learn some new ways of doing things.

To help you reach this goal, a professional rehabilitation team which includes doctors, nurses, therapists, social workers and psychologists will provide:

- Medical diagnosis and treatment of your injury
- Knowledge and training you need to take care of yourself
- Counseling, support, and referrals to other agencies

FAMILY CONFERENCE

Early in your hospital stay, the staff will hold a meeting with you and your family. They will discuss your condition with you and explain your rehabilitation program. You and your family will have a chance to ask questions and express your concerns at that time. Other family meetings will be held as needed during your hospital stay, including a discharge conference to answer any final questions you have before going home.

INDIVIDUALIZED PROGRAM

Soon after you come to Shriners Hospital, you and the staff will set some specific goals for you to work toward during your hospital stay. There will be physical tasks you need to practice, and facts you need to learn. As you reach each goal, it will be recorded in your chart. Setting clear, realistic goals and reaching them will help you see that you are making progress in the gradual process of rehabilitation.

INDEPENDENT LIVING PROGRAM

Toward the end of your stay in the hospital, you may enter the "Independent Living Program" if this is appropriate for your age and injury. You will be expected to take care of yourself just as you would if you were at home. This will give you more experience and confidence with your self-care.

DISCHARGE APARTMENT

Shriners Hospital maintains an apartment where you and those who will be caring for you may stay before you go home. Here you can practice your new routines on your own, with the support of the SCI staff when you need it.

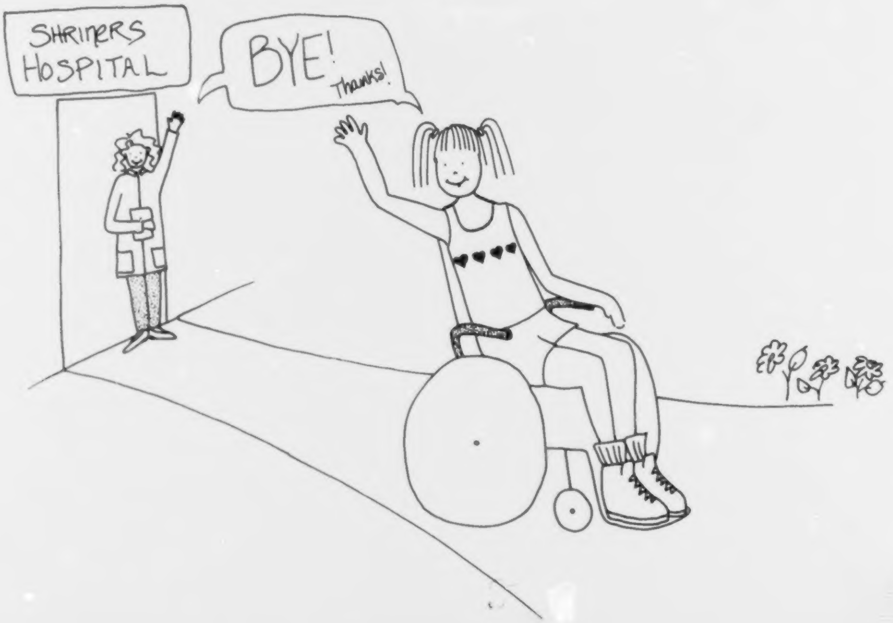
RETURN TO YOUR COMMUNITY

You will be encouraged to go home for short visits, if possible, to see your family and friends and get used to being home again. A home visit will be arranged by a staff member or an agent in your area to see if any changes are needed for a wheelchair or other equipment.

When you leave Shriners Hospital, your family doctor will take over responsibility for your medical care. You are welcome to call the SCI Unit with questions about your routine care which you may have after you go home. Medical problems, however, should be referred to your own doctor.

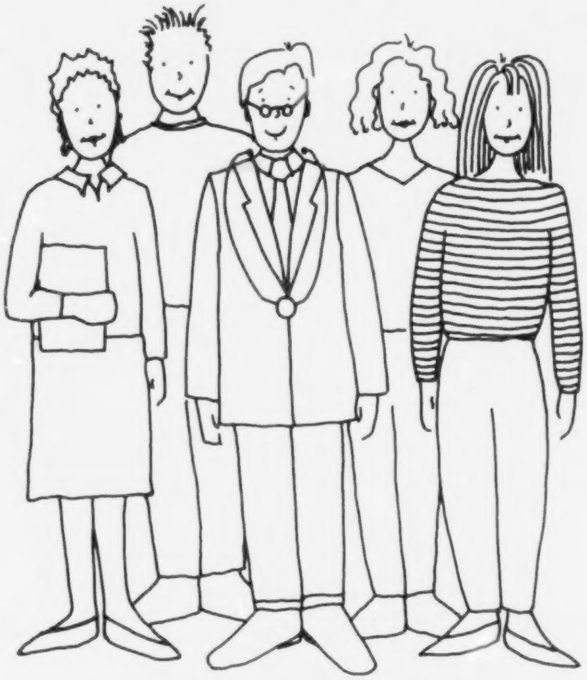
REEVALUATION

After you leave Shriners Hospital, you can return for clinic visits or readmission for evaluation, treatment and/or training, depending on your needs and your circumstances. A complete yearly urinary exam is very important. You may want to work more on therapy skills or learn more about sexuality as you get older. After you reach 18 years of age, you may be referred to an adult rehabilitation hospital in your area if you require hospitalization; however you will be eligible for outpatient clinic care until you are 21.


SHRINERS HOSPITAL
BYE!
Thanks!

THE REHABILITATION TEAM

The staff working with you will be a team of doctors, nurses, therapists, social workers, psychologists, and other professionals as your condition requires. Their role is to give you the training and support you need to reach your goals. The most important members of the team are you and your family. Tell us about what is important to you, your feelings, problems and goals. We want to assist you in any way we can.



Your Doctor(s) is: ____________________

The doctors are responsible for diagnosing and treating any medical problems, such as broken bones, bladder infections, skin breakdown, spasticity, pain, or breathing difficulties.

Your Nurses are: ____________________

The nurses will supervise many aspects of your care. Their main goal is to develop a bowel, bladder and skin care program to help you stay healthy once you leave the hospital.

Your Social Worker is: ____________________

The social worker will help you and your family adjust to the changes in your lives, and help you connect with community support systems to get the care and services you will need.

Your Physical Therapist is : ____________________

The physical therapist will help you reach your highest possible physical ability. You will learn transferring and other mobility skills and ways to preserve and increase your strength and flexibility, with the use of equipment if necessary.

Your Occupational Therapist is: ____________________

The occupational therapist helps you become as independent as possible in self care. You may be given some equipment to help you with your daily activities. A home evaluation may be done to help make your home wheelchair accessible.

Your Recreation Therapist is: ____________________

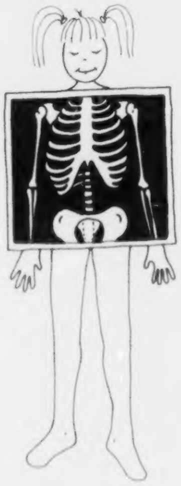
The recreation therapist will help you explore ways to spend your free time that will be fun and satisfying for you, while you are here and when you return home.

Others: ____________________

Other specialists such as respiratory therapists or the dietician may help you with special needs during your stay.

DIAGNOSTIC TESTS

Diagnostic tests are used to find out how your spinal cord injury has affected other parts of your body. On the basis of these tests, the doctors can decide on the best treatment for you. Some tests require special preparation or a trip to another hospital. You will be told more about each test before you have it. Some of the tests often done at Shriners are:



X-RAYS

X-rays are used to find out the extent of bony injury to the spine, and to be sure your spine is healing properly. They may also be taken if other injuries or diseases are suspected.

BLOOD TESTS

Blood may be drawn from your finger or arm at times during your hospital stay to test for chemical changes in your body.

URINE TESTS

Tests of your urine will be done to check for infection or other problems.

URODYNAMIC STUDIES

This is a special test of the urinary system, used to find out how your bladder and its valves are working. You will be taken to another hospital where there is special equipment for the test.

OTHERS

Other studies of the bowel, kidneys, nerves or muscles may be done. These will be explained to you before the tests are done.

SCHEDULE

This general weekday schedule may not hold for every patient. There are no therapies or school on weekends.

7:00	Breakfast
7:30-9:00	Morning care: bathing, dressing, bowel/bladder care
9:00-11:30	Therapies, self-care training, or school
11:30	Lunch
12:00-5:00	Therapies and/or school
5:15	Dinner
6:00-8:00	Recreational activities, free time, group and individual education
8:00-10:00	Evening care: bowel/bladder care, range of motion
10:00	Bedtime

You may have other things you must do during the day, such as weight shifts, breathing treatments, catheterizations, or meetings with the social worker.

THERAPY SCHEDULE

The therapy schedule is posted on a clipboard at the nurses' station, as well as on the wall. You should get in the habit of checking your schedule each day. It is your responsibility to know when your appointments are and to be ready for them on time.

We encourage you to use your time in the hospital to learn as much as you can about your injury and your care. The time will go more quickly and you will be better prepared to take care of yourself when you go home.

UNIT POLICIES

For the safety and comfort of all our patients, we ask that you adhere to the unit policies while at Shriners:

Smoking: There is no smoking on the SCI Unit. If you are a smoker ask about acceptable times and places to smoke.

Visiting Hours: Hospital visiting hours are from 11am to 8pm. One parent may stay overnight with the patient, provided this has been arranged in advance with the Nurse Manager in charge of the SCI Unit. We encourage family and friends to visit at times that will not interfere with your therapy or school schedule, in order to make the most of your time here. It may be necessary to limit the number and frequency of visitors, depending on your condition and the needs of the other patients.

Food: Three meals plus snacks are provided every day. Be sure to fill out your menu and let your nurse or dietician know of any special food needs or requests. We will try to accomodate your food preferences.

You and your visitors are permitted to bring food into the hospital and to heat foods in the microwave oven located in the SCI dining room. There is a limited amount of refrigerator and cupboard space available for food storage. Food should be clearly marked with your name and the date of storage. Storing food in your room is discouraged to prevent odors and pests.

Outings: Outings off the hospital grounds may be arranged during your stay at Shriners to allow for a family visit, recreational time or community reorientation. The maximum time permitted for an outing is 48 hours, and a physician-approved pass must be obtained a few days in advance.

Other than for approved outings, you are expected to remain in the hospital. If you want to leave the SCI Unit for any reason, please let your nurse know where you are going and when you will return.

Phones: Patients and their visitors are asked to use the pay phones to make outside calls. These are located in the front lobby, the clinic waiting room, and the west playroom. You may receive phone calls in your room if you wish. Whenever possible, try to arrange for your family and friends to call at a pre-arranged time when you will be available.

Bedtime: All patients need to be in bed by 10pm on weeknights, 11pm on weekends. Lights and TVs must be off by 11pm on weeknights, 12:30 on weekends. Younger children and those who need more evening care may have to go to bed earlier.

ACTIVITY ATTENDANCE RULES

1. All patients must attend and participate in all activities on their schedules.

2. Patients must arrive at their scheduled appointments on time. On time means no more than 5 minutes late (by the clock in Physical Therapy). This does not mean that it is okay for you to miss the first five minutes of each appointment.

3. Patients must wait 10 minutes for the therapist or social worker to show up. If he/she doesn't show up within that time, that appointment is cancelled, unless the patient wishes to wait longer.

4. If a patient is going to be late or absent, the patient is responsible for calling, or directing their nurse to call the person with whom they have the appointment. If no one calls, the absence or lateness is unexcused.

5. If a patient is absent or late 3 times without an excuse a conference will be set up with the patient to determine what the problem is, and to try to work it out.

PATIENT'S RIGHTS

The patient has a right to considerate and respectful care.

The patient and his parents or legal guardian have the right to obtain from his physician complete current information concerning his diagnosis, treatment and prognosis in terms they can reasonably be expected to understand. They have the right to know by name the physician responsible for coordinating his care.

The patient and his parents or legal guardian have the right to receive from his physician information necessary to informed consent prior to the start of any procedure or treatment, except in emergencies where life-saving measures are required.

The patient and his parents or legal guardian have the right to refuse treatment to the extent permitted by law and to be informed of the medical consequences of such action.

The patient has the right to every consideration of his privacy concerning his own medical care program.

The patient has the right to expect that all communications and records pertaining to his care should be treated as confidential.

The patient has the right to expect that within the reasonable limits of its capacity a hospital must make reasonable response to the request of a patient for services, such as evaluation, service or referral as indicated by urgency of the case.

The patient and his parents or legal guardian have the right to obtain information as to any relationship of his hospital to other health care and educational institutions insofar as his care is concerned.

The patient and his parents or legal guardian have the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his care or treatment; and they have the right to refuse to participate in such research projects.

The patient has the right to expect reasonable continuity of care.

The patient and his parents or legal guardian have the right to expect a discharge plan, whereby his health care requirements may be met following discharge.

The patient and his parents or legal guardian have the right to know what hospital rules and regulations apply to his conduct as a patient.

PATIENT'S RESPONSIBILITIES

PROVISION OF INFORMATION

A patient and his parents or legal guardian have the responsibility to provide, to the best of their knowledge, accurate and complete information about present complaints, past illnesses, hospitalizations, medications, and other matters relating to the patient's health. They have the responsibility to report unexpected changes in the patient's condition to the responsible physician. A patient and his parents or legal guardian are responsible for making it known whether they clearly comprehend a contemplated course of action and what is expected of them.

COMPLIANCE WITH INSTRUCTIONS

A patient and his parents or legal guardian are responsible for following the treatment plan recommended by the physician primarily responsible for the patient's care. This may include following the instructions of nurses and allied health personnel as they carry out the coordinated plan of care and implement the responsible physician's orders, and as they enforce the applicable hospital rules and regulations. The patient and his parents or legal guardian are responsible for keeping appointments and, when the patient is unable to do so for any reason, for notifying the responsible physician or the hospital.

REFUSAL OF TREATMENT

The patient and his parents or legal guardian are responsible for their actions if the patient refuses treatment or does not follow the physician's instructions.

HOSPITAL RULES AND REGULATIONS

The patient and his parents or legal guardian are responsible for following hospital rules and regulations affecting the patient's care and conduct.

RESPECT AND CONSIDERATION

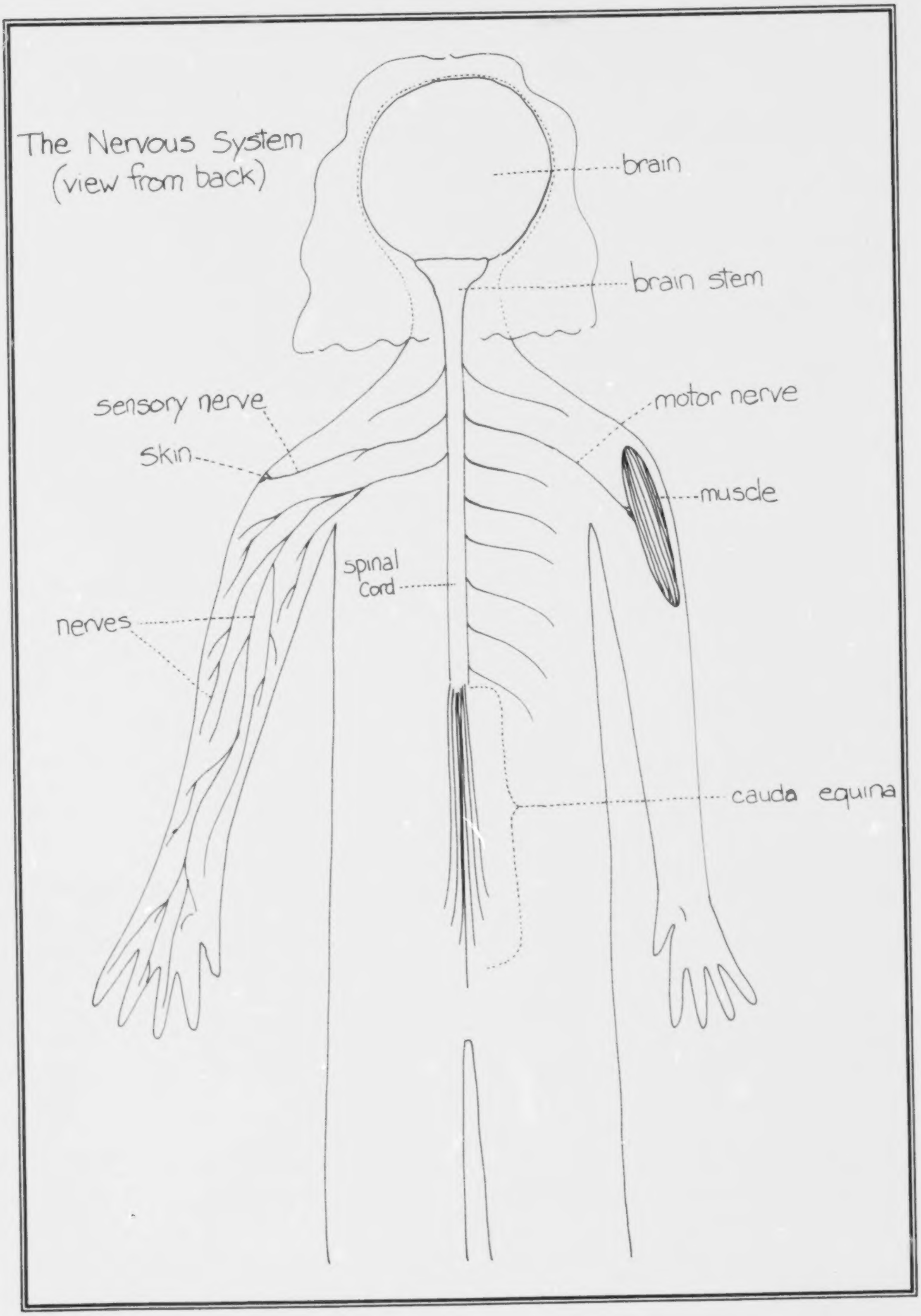
The patient and his parents or legal guardian are responsible for being considerate of the rights of other patients and hospital personnel, and for assisting in the control of noise, smoking, and the number of visitors. The patient and his parents or legal guardian are responsible for being respectful of the property of other persons and of the hospital.

CHAPTER TWO

THE NERVOUS SYSTEM AND SPINAL CORD INJURY

IN THIS CHAPTER YOU WILL LEARN:

- About the nervous system and how it works.
- Why a spinal cord injury impairs sensation and movement.
- The different kinds of spinal cord injury.
- About spasms, spinal shock and dysesthesia.
- About recovery after spinal cord injury.
- Current treatments for spinal cord injury.



The Nervous System
(view from back)

brain
brain stem
sensory nerve
motor nerve
skin
muscle
spinal cord
nerves
cauda equina

THE NERVOUS SYSTEM AND HOW IT WORKS

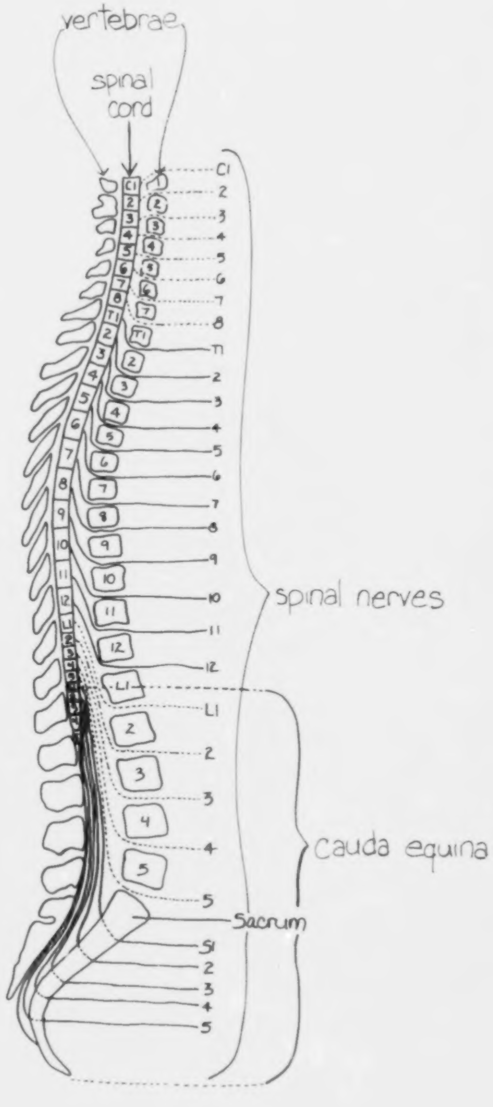
The nervous system is made of the brain, spinal cord, and the peripheral nerves. Together they form a vast network of millions of nerve cells (neurons) which act as a communication system throughout the body.

The spinal cord is a bundle of nerve fibers which go from the brain down through the spinal column, connecting the brain with the rest of the nerves in the body. It is like a central telephone cable, in the sense that messages going between the brain and the peripheral nerves must pass through the spinal cord on the way.

The spinal column, or backbone, is composed of a chain of bones called vertebrae. It has four sections which correspond to the normal curves of the spine: The neck (cervical), chest (thoracic), waist (lumbar) and lower back (sacral) areas. The peripheral nerves which branch out from the spinal cord are also named for these sections.

There are seven cervical vertebrae and eight cervical spinal nerves. There are 12 thoracic vertebrae (those with ribs attached) and 12 pairs of thoracic nerves. There are five lumbar vertebrae and nerve pairs. The five sacral vertebrae are fused into one bone called the sacrum, and there are five corresponding sacral nerve pairs.

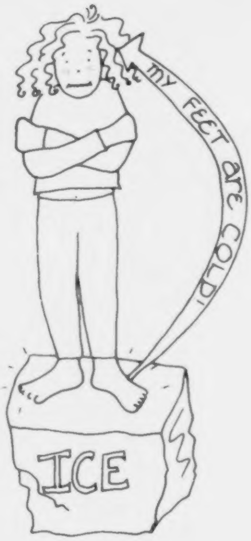
Side view of the
Spinal Cord
and
Spinal Column
(showing relationship of the
spinal nerves to the vertebrae)

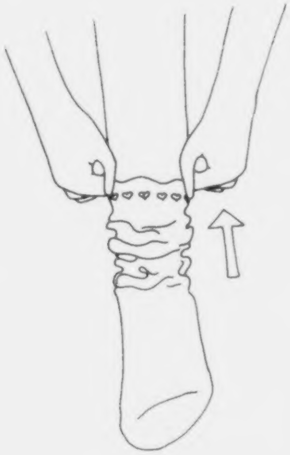


KINDS OF NERVES

There are many different kinds of nerves which do different jobs. In order to understand your spinal cord injury, you should know about these:

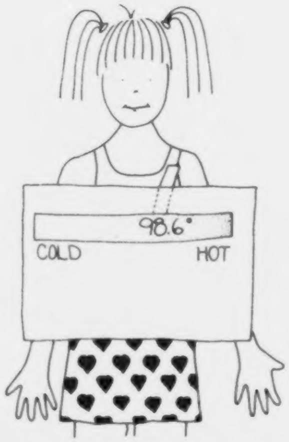
SENSORY nerves enable you to feel. These nerves start in the skin and other organs of the body and carry messages to the brain. The brain interprets these messages as SENSATIONS such as pressure, pain, hot and cold. The brain gets a message: "My feet are cold!"





MOTOR nerves make it possible for you to move. When you decide to move, the message goes from your brain through the motor nerves to your muscles. Your arm reaches out and you put on some socks.

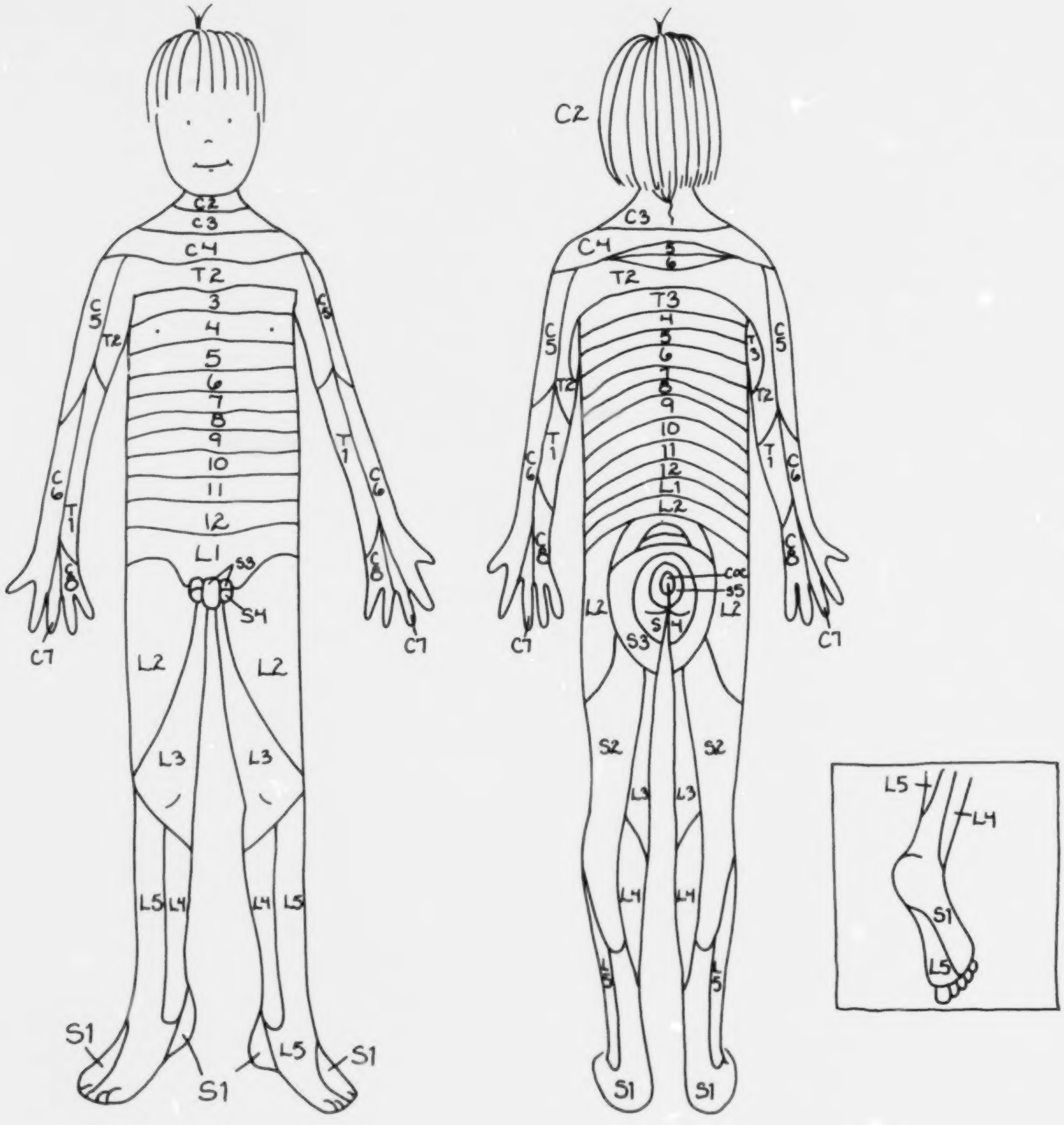
Some nerves work automatically, without you being aware of them. For example, if you are in a cool room, the nervous system acts like a thermostat, telling your blood vessels to tighten up, which helps keep more heat inside your body. This may happen before you even notice that you feel cool. This automatic part is called the AUTONOMIC NERVOUS SYSTEM.



The sensory, motor, and autonomic nerves, along with the brain, regulate everything that goes on in your body, including the many automatic activities you are not aware of, such as blood pressure, temperature, and digestion.

DERMATOME MAP

A Dermatome Map shows us what areas of the body are connected to each set of sensory nerves. The muscles follow a similar, but not identical, pattern of connections with the motor nerves.


C2
C3
C4
T2
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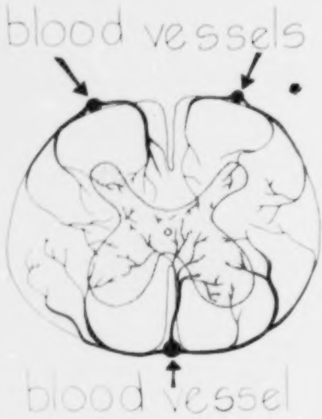
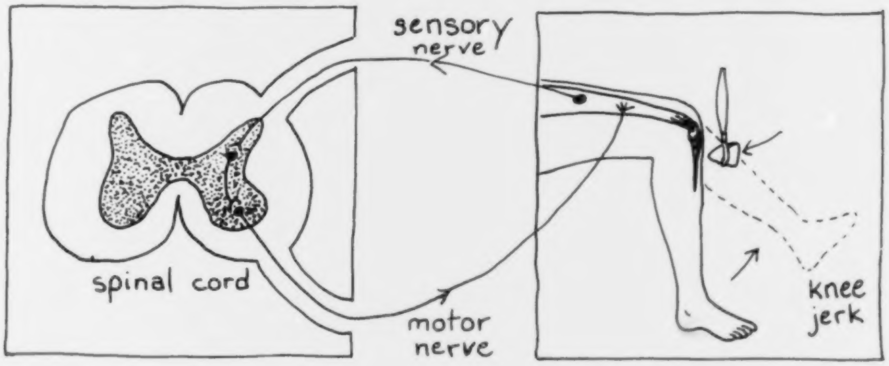
THE SPINAL CORD

The spinal cord is a very delicate, jello-like tissue protected by the hard, bony spinal column. There are blood vessels on either side which provide it with nutrients and oxygen. Very tiny blood vessels extend from these major vessels into the center of the cord so that all the nerves have a blood supply.



REFLEXES

There are some nerves which do not go to or from the brain. They go from various parts of the body to the spinal cord, where they link with other nerves which go directly back to the muscles. This is called a "REFLEX ARC." An example is the involuntary jerk of your knee when it is struck suddenly.



Reflex Arc

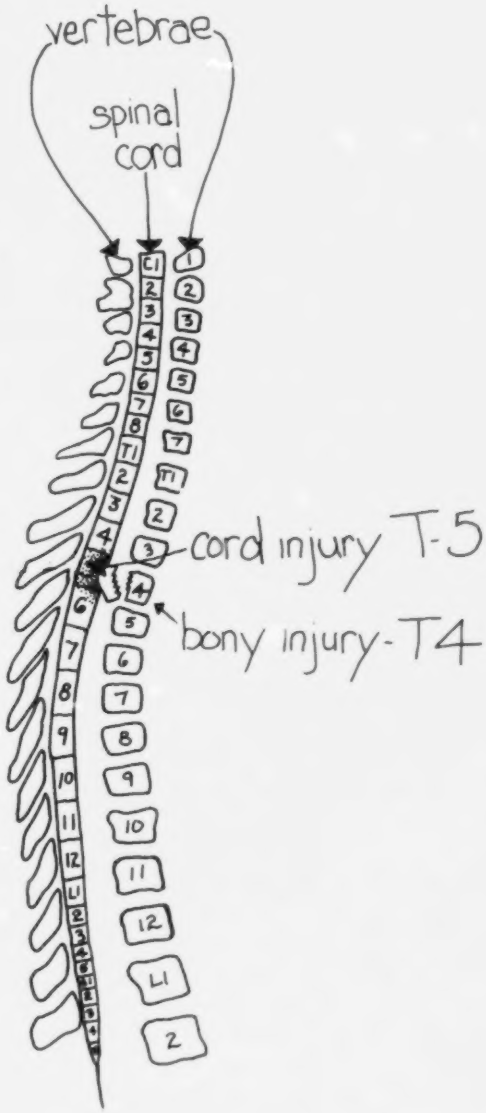
Normally, reflex movements are limited by "inhibitory" messages from the brain. If those messages cannot get through because of spinal cord injury, the reflexes may become exaggerated and repetitive, causing spasms. This will be discussed further under "Spasms".

THE DOUBLE NATURE OF SPINAL CORD INJURY

When there is a spinal cord injury, two different types of injury can occur. The bones of the spinal column (vertebrae) might be broken, crushed, or pushed out of place. This is a "bony injury." Surgery may be needed to repair it; you may have to wear a brace or collar to hold you still and allow the bones time to heal. After a few weeks or months, the bones will mend themselves and you will no longer need the brace.

During the injury, the spinal cord itself may also be damaged. It is rarely actually broken or cut. Usually, the pressure of a sudden impact causes the tiny blood vessels in the cord to break open and bleed. The blood seeps out into the cord tissue, causing it to swell and putting pressure on the delicate nerves. Gradually, this blood will be reabsorbed by the body, but some nerve tissue may have been destroyed by the pressure and bleeding.

The reason this type of injury can be so serious is that once nerve tissue in the cord is destroyed, it cannot grow back. Unlike bone, spinal nerve tissue does not repair itself, and doctors have not yet been able to repair it. Nerve messages cannot travel over or around the damaged area. The feeling and the movement will be missing from the areas of the body which the damaged nerves controlled. This will include part or all of the nerves and muscles at and below the level of injury.



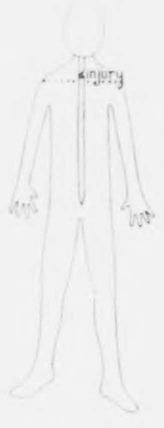
THE DIFFERENT TYPES OF SPINAL CORD INJURY

There are many kinds of spinal cord injury. These depend on where the cord is injured and how much of the cord is affected at that level. Different spinal nerves serve different parts of the body, so the effects of your injury will depend on which nerves are damaged.

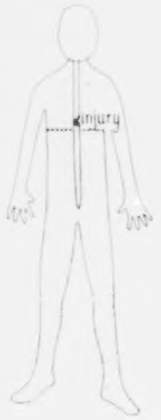
LEVEL OF INJURY

In speaking of a spinal cord injury, we talk about the "level of injury." This means the exact location on the spinal cord where the injury occurred. The cord injury can be at a different level than the bony injury. The amount of movement and sensation you have depends on the level of the CORD injury.

Injuries at or above C-8 produce QUADRIPLEGIA. ("Quad" means "four" - all four limbs will be affected.) At or below T-1, an injury will produce PARAPLEGIA, paralysis of the lower part of the body. By knowing the level of injury, we can predict which areas may be paralyzed, since the zones are approximately the same for everyone.



QUADRIPLEGIA



PARAPLEGIA

COMPLETE OR INCOMPLETE

If an injury is COMPLETE, this means the entire cord is damaged at the level of the injury. There will be no sensation or voluntary movement below the injury, though there may still be reflex activity or spasticity. An INCOMPLETE injury means only part of the cord was damaged, and there may be varying degrees of sensation or voluntary movement below the injury. It may take several weeks or months to determine just how much movement will return. (See the section on "Spinal Shock.")

SACRAL SPARING

If your injury is incomplete you may have specific areas you can feel or move below your injury. An important example of this is "sacral sparing." If the sacral nerves remain intact, you may have some sensation and/or function in your groin, bowels and genitals. This will enable you to be more aware, and perhaps be more in control, of bowel, bladder and sexual functioning.

Frankel Classification System

Doctors use a system called the Frankel Classification System to quickly identify different degrees of injury.

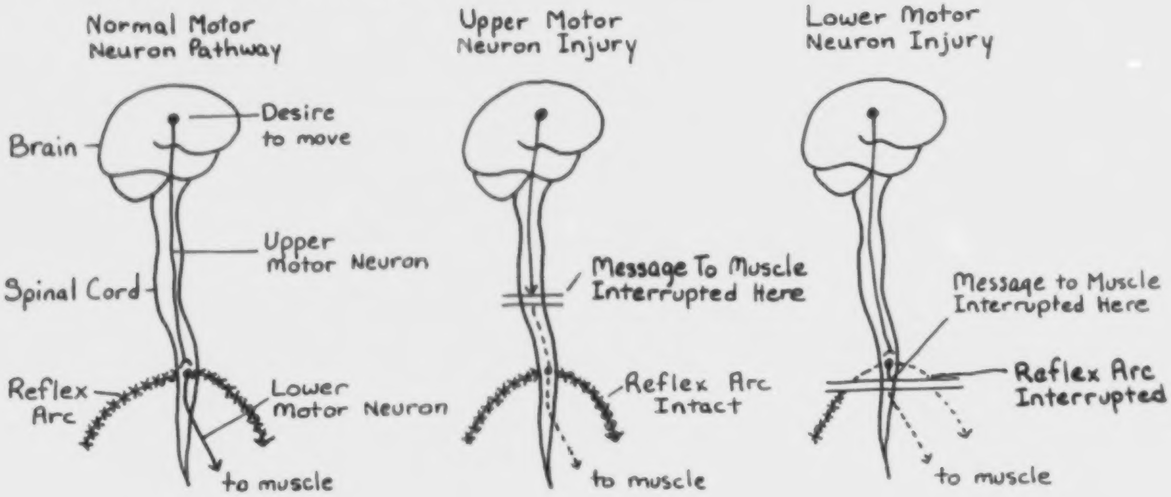
Frankel Class	**Degree of Injury**
A	complete (no movement or sensation)
B	sensation preserved
C	some movement (but non-useful)
D	some useful movement preserved
E	full recovery of movement/sensation

UPPER OR LOWER MOTOR NEURON INJURY

Movement is controlled by the motor nerve tracts, which carry nerve messages from the brain to the muscles, as explained earlier. There are two or more nerves in a motor nerve chain from the brain to the muscle. The UPPER Motor Neurons (nerves) extend from the brain into the spinal cord. There they link up with the LOWER Motor Neurons, which extend from the spinal cord to the muscles.

Injuries above L-1 generally affect the Upper Motor Neurons, while those below L-1 usually interrupt the Lower Motor Neurons. Some injuries may combine upper and lower neuron damage. There are some important differences in how these two types of injury affect your body.

If your injury is "Upper Motor Neuron," the reflexes will still operate below the level of the injury and there may be spasticity. The muscles below the level of injury including those of the bowel and bladder will still have tone (but probably not voluntary control). At the level of injury, the muscles will be flaccid. Above the level of injury, movement and sensation will be normal.


Normal Motor Neuron Pathway
Upper Motor Neuron Injury
Lower Motor Neuron Injury
Brain
Desire to move
Upper Motor Neuron
Spinal Cord
Reflex Arc
Lower Motor Neuron
to muscle
Message To Muscle Interrupted Here
Reflex Arc Intact
to muscle
Message to Muscle Interrupted Here
Reflex Arc Interrupted
to muscle

If the injury occurred below L-1, there may be damage to the "Lower Motor Neurons." Because the reflex arcs are interrupted by this type of injury, there will be no reflexes and no spasms at or below the injury, and the bowel and bladder sphincters will usually be flaccid. Above the level of injury, movement and sensation will be normal.

There are some important differences in your care depending on whether your injury is upper or lower motor neuron. These differences will be explained as you learn about your bowel and bladder programs.

SPINAL SHOCK, SPASMS, AND DYSESTHESIAS

SPINAL SHOCK

Right after an injury, the spinal cord goes into "shock" and many nerve functions stop completely, including reflexes below the injury. This is called "SPINAL SHOCK." As the swelling goes away, some nerves may get back to normal and some feeling or movement may come back. This can take anywhere from a few weeks to a year or more. This is why it is not possible to know right after an injury exactly how much damage is permanent. You may notice changes in your movement and sensation for some time. Be sure to tell your doctor or nurse about any changes you notice.

SPASMS

The presence of spasms and sphincter tone are indications that spinal shock is resolving. Spasms are sudden involuntary movements in the muscles below your injury. They result from the stimulation of reflexes. Because of the injury, you are not able to control or inhibit the reflex activity and it becomes exaggerated and repetitive.

Unfortunately, spasms do not mean that you will be able to move these areas voluntarily. But they can be useful in helping you do things later on. They also help keep your muscles in better shape and improve your blood circulation. If spasms are severe, however, they can be painful and bothersome. There are some medications and other measures that can be taken to reduce them.

DYSESTHESIA

You may have strange sensations or pain called dysethesia which seems to come from areas of your body below the injury. This is particularly common right at the level of injury, where tingly or partially numb areas may occur. It is caused by partially damaged nerves in the spinal cord, not in the area of the body where the sensation seems to be. If these become very bothersome, medication or sometimes surgery can help. You may find that areas where you do have sensation seem more sensitive than before your injury. This is called hyperesthesia and it is quite common after SCI.

ABOUT RECOVERY AFTER SCI

Right after a spinal cord injury, it is hard to know how much recovery you will have. People have experienced degrees of recovery for several months or even a few years. However, for most people, the greatest recovery occurs within a few days or weeks after injury.

Doctors try to determine as closely as possible the extent of the damage, using x-rays and neurological tests. Based on the best information they can get, your doctors will let you know as much as they can about your chances for recovery.

Full recoveries from spinal cord injury are rare, but they do occur. If the paralysis is the result of temporary pressure on the cord, some movement may return as spinal shock wears off. A few individuals have recovered partially or completely even when the injury seemed medically to be permanent. So far, doctors have no technique for restoring spinal nerve tissue once it is destroyed. Research is being done in this area and some promising results have been achieved with laboratory animals.

There are many factors which determine the final outcome of a spinal cord injury. Some are under our control, and some are not. Our philosophy is to do everything we can to insure the greatest possible recovery. At the same time, we feel it is important to get on with living in the present and learn to deal with things as they are, even while hoping for improvement. By learning to cope with the effects of your injury, you are not giving up hope. On the contrary, you are giving yourself and your body the best chance for recovery by maintaining your health and a good attitude about life.

CURRENT TREATMENTS FOR SPINAL CORD INJURY

Once an injury has occurred, current treatment is aimed at preventing further damage and preserving as much function as possible. You may have surgery to stabilize the broken bones and reduce pressure on the spinal cord. A brace may be used to immobilize your spine and protect your spinal cord from further injury while the bones heal. The doctors will monitor your healing with x-rays and neurological evaluations. Therapies to keep your body flexible, strong and healthy will also allow for the greatest possible return of function.

A technique called "Functional Neuromuscular Stimulation" is being studied to find out if spinal cord injured people can stand and walk with the help of electrical stimulation to their paralyzed muscles. Electrodes are embedded in their muscles and attached to a computer. The computer is programmed to stimulate the right combination of muscle groups to allow for useful movement. The technique may someday allow greater mobility for certain patients, though at this time it is still experimental.

You may hear about miracle cures with diet, positive thinking, or other techniques. In some cases, these injuries may not have been as severe as originally diagnosed. We urge you obtain a sound medical opinion about any such treatment before investing your time, money and hopes.

There is hope that sometime in the future, spinal injury will be curable. Current research includes attempts to stimulate spinal nerve tissue to regenerate. Several magazines devoted to the needs of disabled people report each month on the new research into treatments for SCI. You will no doubt want to keep informed about this type of research.

NERVOUS SYSTEM CHECKLIST

What is the spinal cord? What does it do?

What is a SENSORY nerve? A MOTOR nerve? What does the AUTONOMIC nervous system do?

What is a REFLEX ARC?

What are the two different tissues injured in a spinal cord injury?

What do we mean by LEVEL OF INJURY? What is the level of your injury?

What is the difference between QUADRIPLEGIA and PARAPLEGIA?

Is your injury COMPLETE or INCOMPLETE?

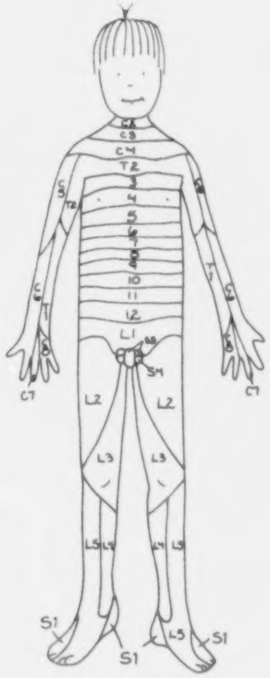
Is your injury UPPER MOTOR NEURON or LOWER MOTOR NEURON?

What is SPINAL SHOCK? Why does it take a while before the exact extent of your injury can be known?

What is a SPASM?

Do you have DYSESTHESIA, HYPERESTHESIA, SACRAL SPARING?

Zone Exercise: In which zones do you have sensation or movement? Have your nurse go over the zones with you and help you determine just how much sensation you have. Mark on the zone map, or have someone mark for you, any areas of your body that have sensation or movement.

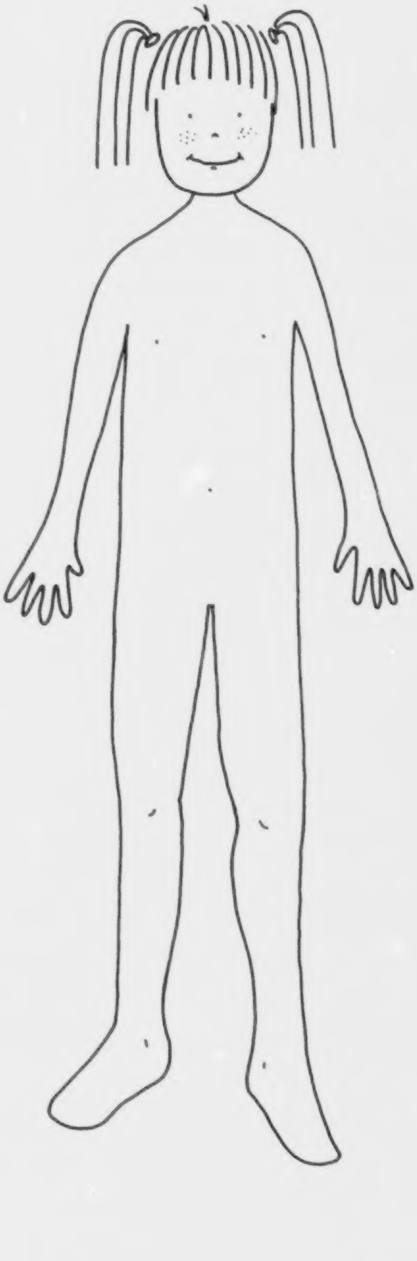


CHAPTER THREE

SKIN CARE

IN THIS CHAPTER YOU WILL LEARN:

- About the skin and its purpose.
- The causes of skin breakdown.
- The reasons special skin care is needed after SCI.
- How to protect your skin after SCI.
- What to do about skin problems.



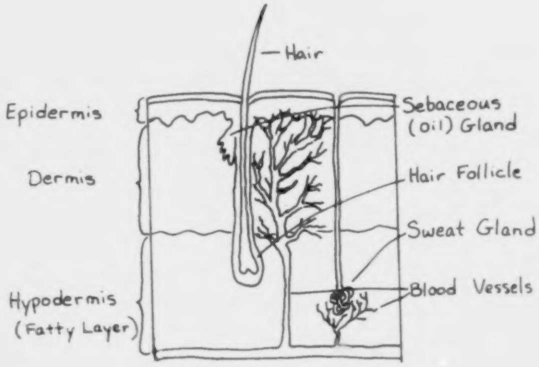
WHAT IS THE SKIN?

The skin is an organ of several layers which covers your whole body, keeping germs out and important substances in. By sweating, it also helps to get waste products out of the body and to regulate your temperature. Normally, keeping your skin clean is all you have to do to keep it healthy. After SCI, skin care becomes a very important part of your daily program.

The main layers of the skin are these:

The *epidermis*, or surface layer; the *dermis*, an underlying layer of dense connective tissue; and the *hypodermis*, which contains loose connective tissue and fat cells. Hair follicles, sweat glands, and sebaceous (oil) glands extend from the dermis to the surface.

A network of blood vessels extends to the inner part of the epidermis to provide nutrients and oxygen to make new skin cells. As surface cells dry up and flake away, they are replaced by new cells.



THE EFFECTS OF SCI ON THE SKIN

After a spinal cord injury, you may have decreased or absent sensation (feeling) below the level of your injury. This increases the risk of injury to your skin. For example, you may not feel if the bath water is too hot, or if a sharp object is poking you. Your skin may become injured or burned without you knowing it.

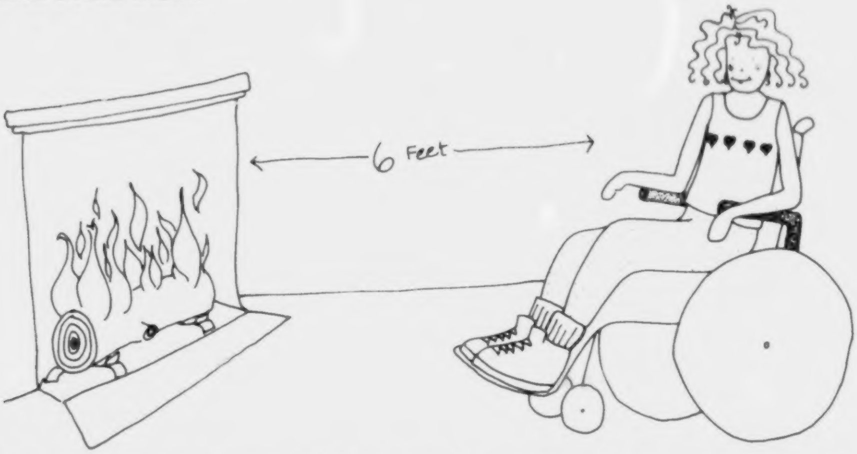
Because you move less, your skin will get more pressure in some areas than it did before. Constant pressure can damage your skin and cause sores.

Normally your skin is constantly rebuilding itself and shedding its outer layers. After SCI there is a reduced blood supply to the surface, and the skin does not rebuild itself quite as well as before. Your skin will become thinner and more delicate. Thin skin can be more easily injured and will heal more slowly.

CAUSES OF SKIN PROBLEMS AFTER SCI

Pressure is the most common cause of skin problems after SCI. Pressure cuts off the blood supply to the skin. Without fresh blood, the tissue dies within hours. The damage often starts under the surface, appearing as a reddened or bruised area. Soon after, a blister forms as the layers of skin separate. An opening ("pressure sore") eventually develops on the surface. This open area can get infected. Any infection is dangerous and can cause serious problems if not treated. *(See Chapter 9 on Complications for a more thorough explanation of how sores develop and what to do to prevent and treat them.)*

There are other dangers to your skin as well. Friction from tight clothing, sheets or wheelchair wheels can cause scrapes or blisters. Wetness from perspiration or incontinence increases friction and is a breeding ground for germs. Heat from bath water, fireplace, car vent, hot water bottle or sun can burn you without you feeling it. Exposure to cold or the draft from an open air vent in cold weather can cause frostbite. If your sensation is impaired, you need to be aware of such possible dangers and avoid them.



THE IMPORTANCE OF SPECIAL SKIN CARE AFTER SCI

It is very important that you learn to protect your skin and to treat any injury right away. Any opening in the skin, regardless of cause, can get infected. This can be life-threatening if not treated promptly. If you do not take care of a sore you may end up needing surgery to repair it; this is time-consuming and very expensive. A deep sore almost always leaves a large, disfiguring scar which is not as strong and healthy as normal skin; this increases the chances of more sores.

Fortunately, these problems can be prevented if you do good skin care every day. If you make your skin care into a daily habit, as automatic as eating and sleeping, you will be able to avoid one of the most serious health problems of people with SCI.

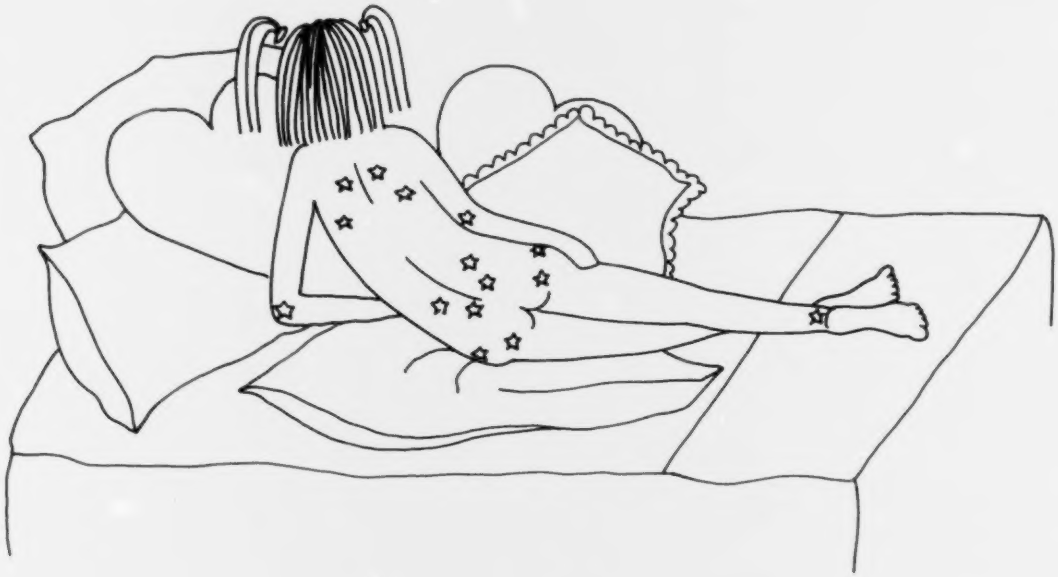
THREE STEPS TO HEALTHY SKIN

1. RELIEVE PRESSURE
    - Weight Shifts
    - Good Posture
    - Good Positioning
    - Padding
2. EAT WELL
    - Weight Control
    - Vitamins, Proteins, and Fluids
3. DAILY SKIN CARE AND OBSERVATION

RELIEVE PRESSURE

You MUST give your skin a chance to breathe and renew its blood supply at regular times throughout the day and night. You will be taught how to do "weight shifts" in your wheelchair so you can stay in the chair all day. When in bed, a turning schedule and careful positioning will help protect your skin.

The illustration shows the points on your body where pressure sores are most likely to occur.

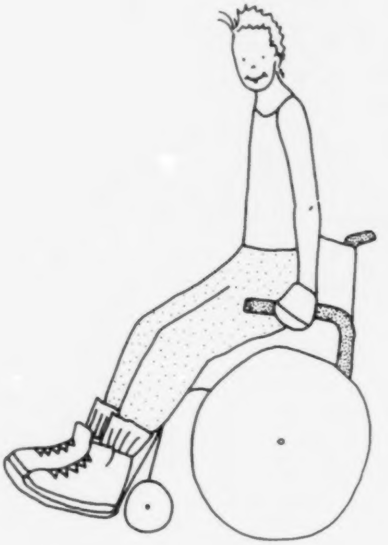


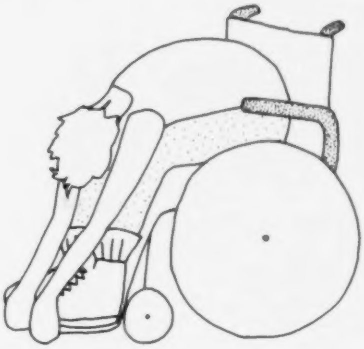
WEIGHT SHIFTS

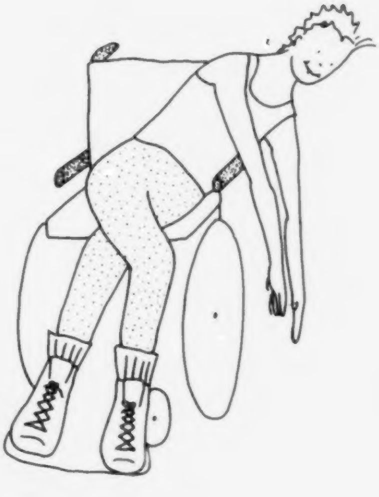
There are several ways to do weight shifts. Which way you do it (and how often) will depend on your level of injury, type of wheelchair, and how much pressure your skin can tolerate.

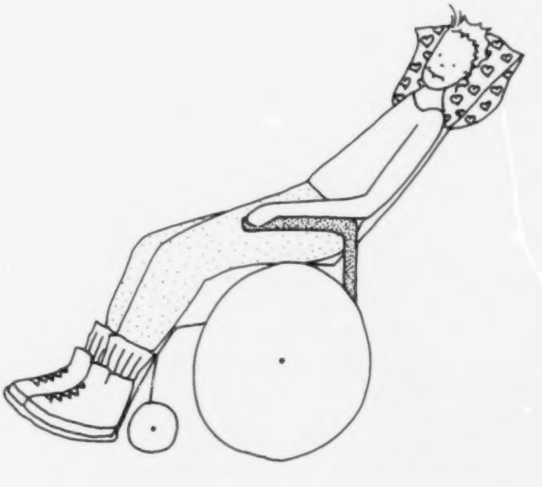
Whichever way you use, be sure to relieve the pressure for at least a minute - no cheating! Your therapist or nurse will show you which weight shift method is best for you.

WEIGHT SHIFTS



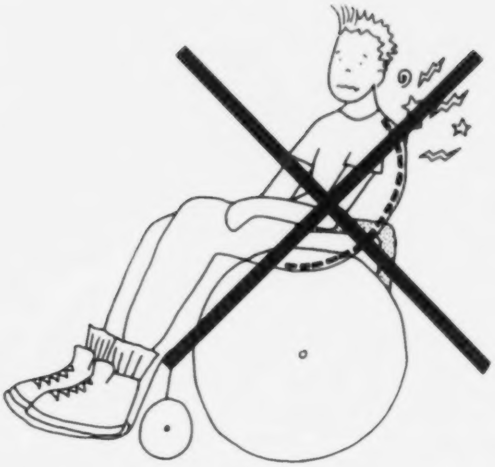






POSTURE

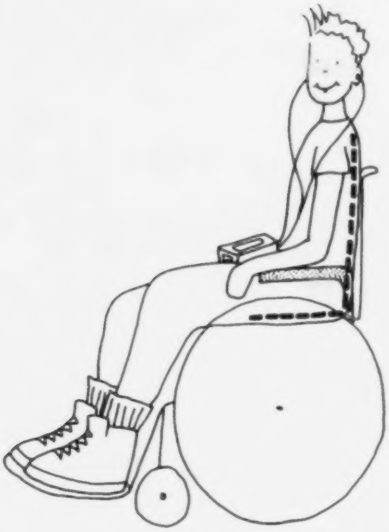
POOR POSTURE



When you slump in your chair, the weight of your body falls on your poorly padded sacrum, the large flat bone at the base of your spine, the most frequent site of pressure sores. If you find it hard to maintain good posture, you or your helper will have to reposition you every so often.

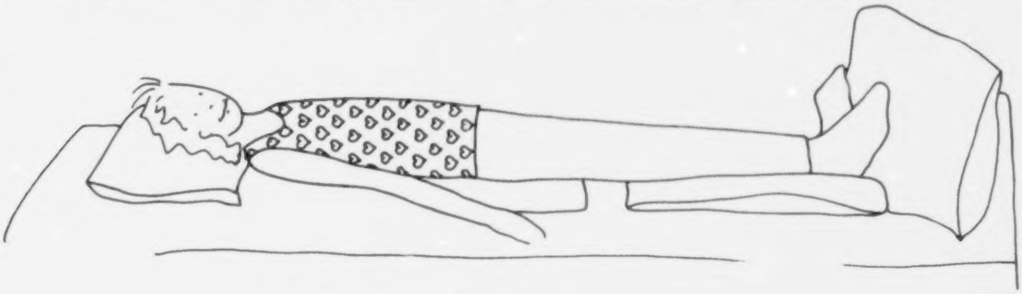
GOOD POSTURE

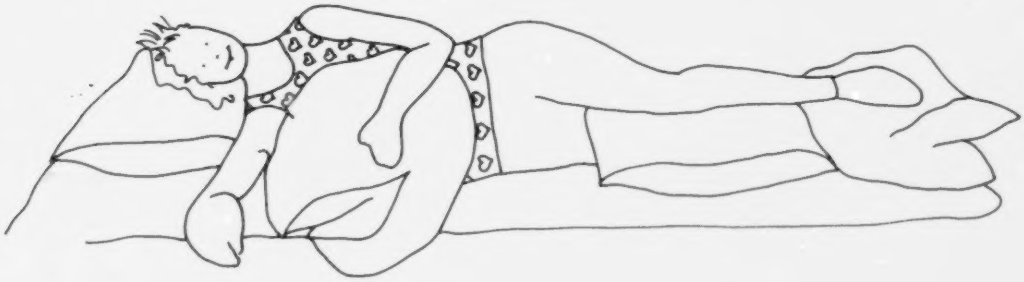
The body weight is distributed to your ishia (sitting bones) and the fatty pads of your buttocks and thighs. This position also allows you to breathe more freely and avoids pressure on your internal organs.



POSITIONING

Good positioning helps keep your body in good alignment and your joints flexible. But most important, it keeps your pressure points from getting too much pressure. Since you spend so much time in your chair, it is better to stay off your back when in bed. All joints should be in their natural position and properly supported with pillows or splints. The following illustrations are examples of good positioning.



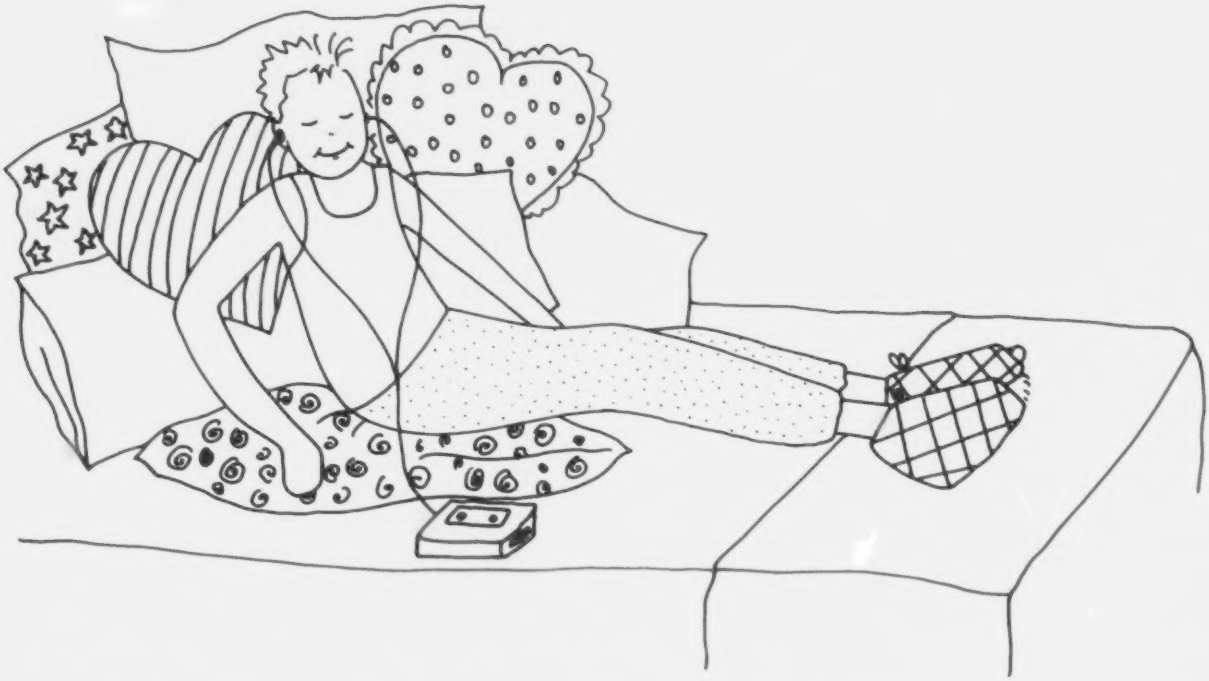


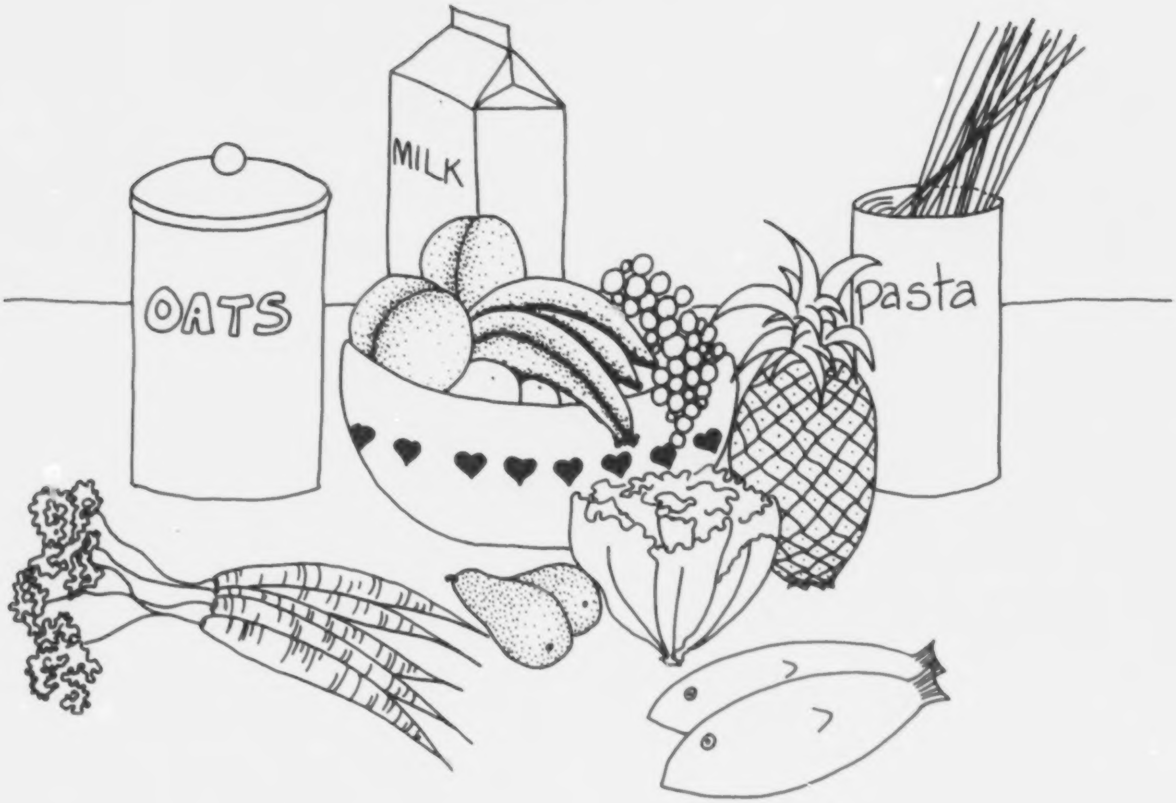
PRONING

Proning means lying on your stomach. This is the best position for sleeping for several reasons. It allows you to go several hours without turning; this means you do not have to wake up during the night. Proning also can help reduce spasms and tightness in your hips and knees. It may take some practice for you to feel comfortable in this position, but careful positioning should make it possible for you to prone at least a part of each day.

PADDING

Use your wheelchair cushion whenever you are sitting, whether in your wheelchair, in the car or on another chair. Use pillows, heel and elbow protectors, eggcrate mattresses, and any other devices or methods you need to reduce pressure, rubbing, and irritation. If you have spasms which rub your feet on the sheets, a sheepskin or heel protectors will help reduce friction and protect your heels.





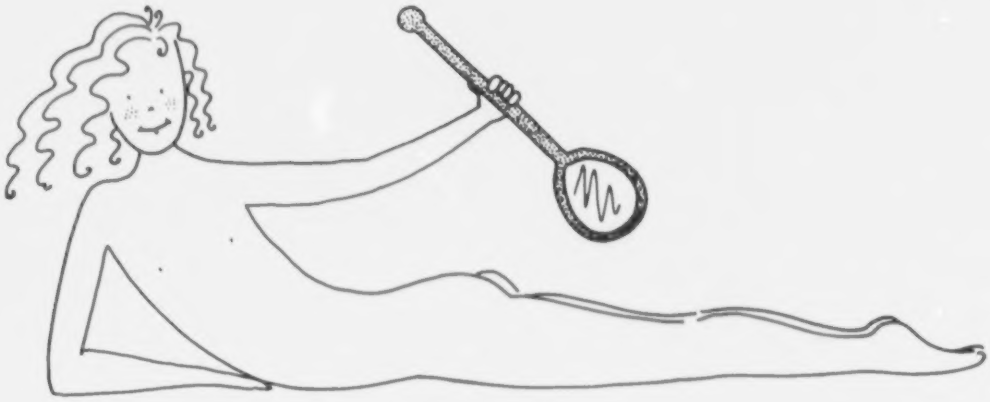
EAT WELL

To help your skin stay healthy and strong, eat nutritious foods with enough protein, fluids, and Vitamins A, C and E. Make every effort to stay at your ideal weight. Extra weight puts more stress on your skin (and every other system). Being underweight means you have less padding and more pressure on your pressure points.

DAILY SKIN CARE AND OBSERVATION

The skin is always shedding old cells and perspiring. Wash your skin gently every day, dry thoroughly, and use lotion if needed to soften any dry areas. Clean and dry your skin right away if it gets wet or dirty.

Toe nails may become thicker and break easily due to changes in your circulation. Trim your toe nails straight across and wear roomy shoes to avoid ingrown toe nails. You may need to wear shoes a size larger than before your injury. Inspect for cracks, scaley areas, or rash between your toes. Check your nails for breaks or red, swollen areas which are signs of an ingrown toe nail. Get treatment for an ingrown nail or any other problem right away. Such problems can cause increased spasms or even dysreflexia. *(See Chapter 9 on Complications for more about dysreflexia, a medical emergency.)*



Daily Skin Check

Using a mirror, check your entire body every day for reddened areas, cuts or scratches, blisters, rashes, pimples, or sores of any kind. If you use a condom catheter, change it at least daily and inspect the area carefully for redness or broken skin. If you find anything wrong, do something about it right away so it does not get worse.

WHAT TO DO ABOUT SKIN PROBLEMS

If you notice a reddened area which does not go away after relieving the pressure, you need to give that area a chance to heal. The only way to do that is to STAY OFF THE AREA for as long as it takes to bring back its healthy, normal color. That could be a few hours, or a few days. After that, measures should be taken to prevent this from happening again. You may need to do weight shifts more often, get a different type of wheelchair cushion, or wear looser clothes.

You may not like the idea of staying in bed and missing school or work, but there is a real danger that the sore will get worse, and more time will be lost. If you take one or two days when the problem is small, you can save yourself more time, money and unhappiness in the long run. *(See Chapter 9 on Complications for more about Pressure Sores.)*

For other skin problems such as minor cuts, burns, pimples, blisters, or rashes, cleanse them carefully, (do not pop blisters) apply a sterile dry bandage, and check daily to be sure they are healing properly. If swelling, increased redness, or pus appears, or if they do not heal in a few days, tell your doctor. Your slower circulation can slow down healing; your lack of sensation can keep you from feeling the pain of an infection. Even small wounds, if persistent, should be seen by a doctor or nurse. Do not try to remove an ingrown toe nail. See a foot doctor for treatment. A rash might mean you have a drug allergy, a fungus infection, or some irritant in your environment. Talk to your doctor if you get a rash.

SKIN CHECKLIST

What does the skin do?

How does SCI affect the skin?

What is the effect of constant pressure on the skin?

What are some other causes of skin problems besides pressure?

Why is it so important to protect your skin?

What are three steps you can take to prevent skin problems?

What would you do if you noticed an area on your skin which stayed red even after you relieved the pressure?

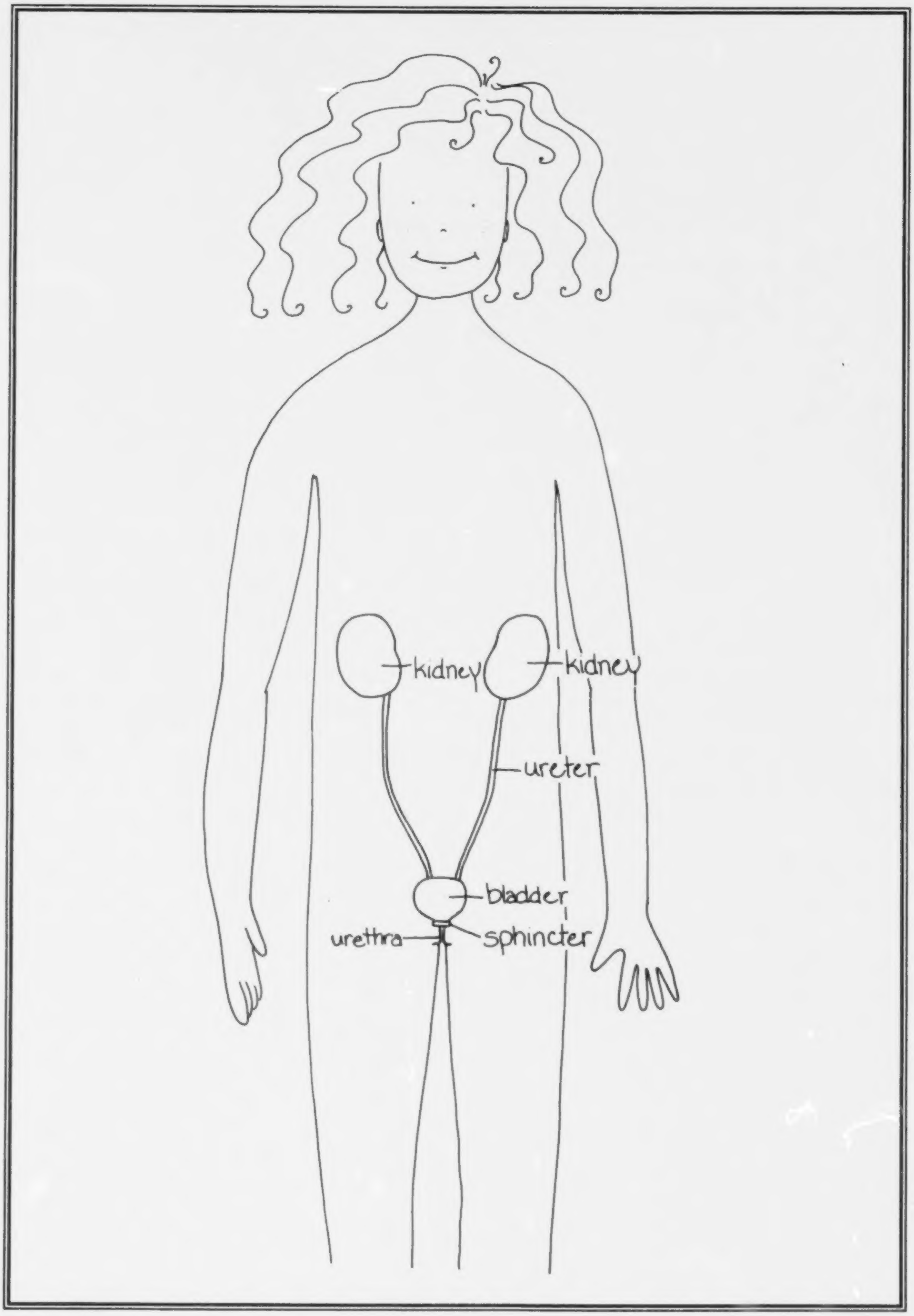
What would you do if you had a sore, burn or blister on an area of your body where you do not have sensation?

CHAPTER FOUR

BLADDER CARE

IN THIS CHAPTER YOU WILL LEARN:

- How the urinary system works.
- How SCI affects the urinary system.
- Why it is important to maintain your bladder care program.
- How to protect your bladder from infection.
- The signs of bladder or kidney problems.


kidney
kidney
ureter
bladder
urethra
sphincter

HOW THE URINARY SYSTEM WORKS

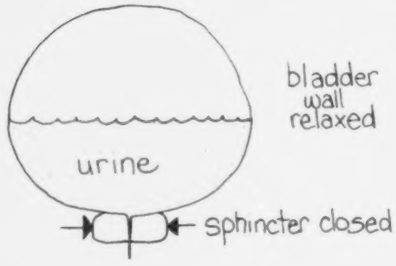
The urinary system is made up of the kidneys, ureters, bladder, sphincters, and urethra. It filters waste products from the blood and removes them from the body in the form of urine.

The kidneys are the filters which draw wastes from the blood and form the urine. The ureters are narrow tubes which drain the urine from the kidneys into the bladder. The bladder is a balloon-like muscular sac where the urine is stored until it is expelled from the body during urination. The urethra is a tube leading from the bladder to the outside of your body. There is a donut-shaped muscle called a sphincter (pronounced SFINK-ter) at the opening of the urethra which keeps the urine from leaking out of the bladder.

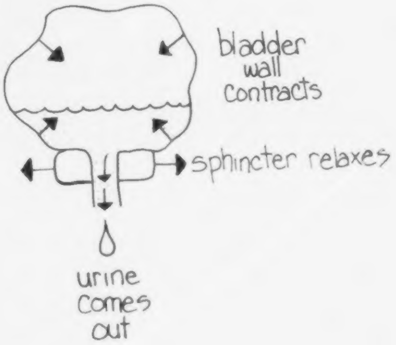
THE PROCESS OF URINATION

In order for you to empty your bladder (urinate), the bladder needs to contract and the sphincter to open at the same time. The contraction of the bladder is controlled by automatic nerves. The closing or opening of the sphincter is controlled by voluntary (motor) nerves. Normally, you have voluntary control over the sphincter, so you can hold in the urine until you get to the bathroom.

bladder at rest:



normal urination:



THE EFFECT OF SCI ON THE URINARY SYSTEM

After SCI, most people lose control of their urination. This is because the nerve messages between the brain and the bladder are interrupted at the level of injury.

Your bladder may become flaccid, which means it loses its ability to contract and expel urine on its own; or it may become spastic, contracting automatically when it is full.

The sphincter may become relaxed, allowing urine to leak out continuously; or it may become spastic, preventing urine from being expelled when the bladder is full.

You may or may not be able to tell when your bladder is full, and you may or may not be able to control the sphincter which holds in the urine.

As you can see, there are several factors which determine how much control you will have over urination. After SCI, a bladder care program is usually needed to be sure the bladder is emptied completely at regular intervals and to avoid uncontrolled wetting.

MEDICAL MANAGEMENT OF YOUR URINARY SYSTEM

While you are in the hospital, you will have some tests which will tell the doctors exactly how your injury has affected your urinary system. Samples of your urine will be tested, and special x-rays will be done to observe how your bladder and sphincter are working.

Based on these tests, your doctors will prescribe a BLADDER PROGRAM. Your nurses will do your bladder care at first. Later they will teach you how to do it or to teach others to help you. As your nervous system recovers from "spinal shock," your bladder may change and your program will change too. By the time you go home, you or your caretakers will be taught how to do your bladder care and to prepare the equipment you will need at home.

Kidney problems are common after SCI, and they can be very serious. Once a year, you will need to have a urologist (urinary doctor) check to be sure your kidneys are healthy. Your doctor may want to test your urine more often to check for bladder infections. Also, you need to learn to observe for any signs of urinary problems and report them promptly to your doctor. Most serious problems can be prevented by careful, consistent bladder care and regular check-ups to detect disease in its early stages.

THE IMPORTANCE OF MAINTAINING YOUR BLADDER CARE PROGRAM

It is very important that you maintain your bladder care program for these reasons:

- If urine is allowed to back up into the kidneys ("urinary reflux"), serious kidney damage can result. Kidney disease is a potential problem for people with SCI, and it can be fatal. *(See Chapter 9 on Complications for more about kidney disease.)*

- Infection can develop in the bladder if urine is allowed to remain too long. Bladder infection can lead to serious illness and kidney damage if it is not treated promptly.

- Solid mineral crystals ("stones") can form in the urinary system if the urine is too concentrated. These can block the flow of urine and cause serious problems.

- Losing control of your urine is embarrassing and irritating to your skin.

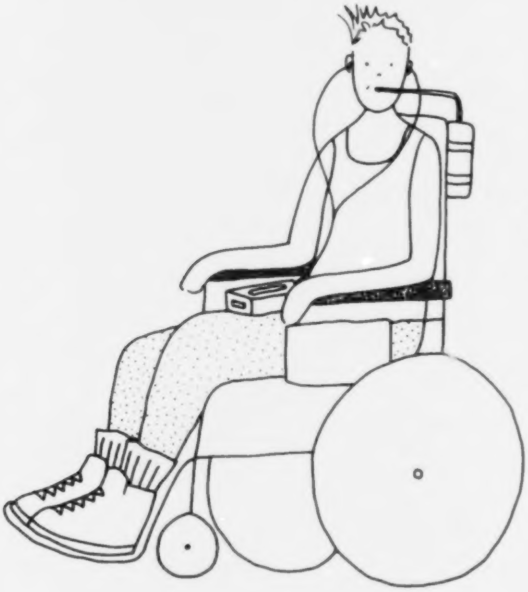
HOW TO KEEP YOUR URINARY SYSTEM HEALTHY

1. DRINK FLUIDS AND EAT WELL
2. MAINTAIN GOOD HYGIENE
3. OBSERVE URINE DAILY

DRINK FLUIDS AND EAT WELL

Taking in enough fluid is an important part of your bladder program. You need water to keep your blood pressure up. (Blood pressure must be above a certain level in order for your kidneys to work.) Water dilutes your urine so you are less likely to form stones. With plenty of fluids, the urinary system is flushed out more often, reducing the chance of infection.

You may be told to limit your fluids in order to regulate your bladder program. This does not mean "drink as little as possible." Even with a fluid limit, the amount suggested may be more than you would normally drink. It is important to drink as much fluid as you are allowed, at fairly regular intervals during the day, to keep the urinary system working well. You may have to remind yourself to drink a glass of fluid every hour or so until this becomes a habit for you.

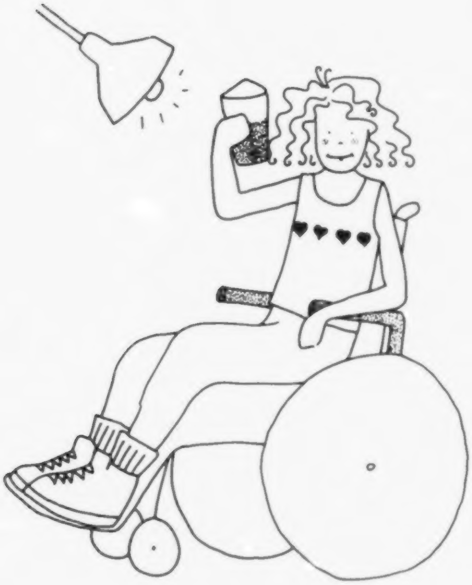


It will also help to follow these food guidelines:

- Reduce salt as much as possible. (Salt holds fluid in the body and makes the kidneys work harder.)
- Avoid eating too much protein, which increases certain toxins in the urine. *(See Chapter 6 on Nutrition for more about protein.)*
- Ask your doctor about avoiding dairy products. Excess calcium may contribute to kidney or bladder stones in some people.

MAINTAIN GOOD HYGIENE

Keep your body and all your equipment very clean. This will help keep germs and infection out of the bladder. Especially when you use a catheter, you need to use "clean technique," a procedure which greatly reduces the number of germs that enter the bladder. Germs are invisible, but they can do a lot of damage. You may need to learn to think in stricter terms about cleanliness than would usually be necessary.



OBSERVE URINE DAILY

Normal urine is crystal clear, pale yellow to pale amber in color, free of particles, and has a fresh, mildly acidic odor. You will need to look at your urine every day and watch for any changes.

SIGNS OF BLADDER INFECTION

- Dark, cloudy, or bloody urine
- Strong or foul odor
- Smaller amounts of urine than usual
- Fever, nausea, vomiting
- Pain, burning, or urgency if you have sensation
- Leaking of urine between catheterizations

SIGNS OF KIDNEY DISEASE

- Pain in mid-back region if there is sensation
- Unusual swelling of feet, legs, or hands
- Dark circles around eyes, or dark tinge to skin
- Urine scant in amount and dark

OTHER SIGNS TO WATCH FOR:

- Grit or particles inside the catheter or drainage tubes
- Unusual difficulty inserting catheter
- Decreased stream or dribbling if you usually urinate without a catheter

You should notify your doctor immediately if any of these signs appear. *(See Chapter 9 on Complications for more about kidney and bladder problems.)*

BEST COPY AVAILABLE

URINARY CHECKLIST

Describe the function of the kidneys, ureters, bladder, urethra, and sphincter.

How has YOUR urinary system been affected by SCI?

Why is it very important to maintain your bladder care program? (There are at least 4 reasons.)

Why is it important to drink enough fluids?

How much fluid should YOU drink each day?

What are the signs of bladder infection?

What are the signs of kidney disease?

Name three measures you can take to prevent bladder infection.

Why is it important for you to have yearly urinary check-ups for the rest of your life?

Demonstrate or talk the nurse through your catheterization procedure.

Demonstrate or talk the nurse through the procedure for preparing your catheterization supplies.

INTERMITTENT CATHETERIZATION PROCEDURE USING CLEAN TECHNIQUE

PURPOSE: To empty the bladder of urine without introducing infection into the bladder. To prevent incontinence of urine; to avoid damage to the bladder and kidneys.

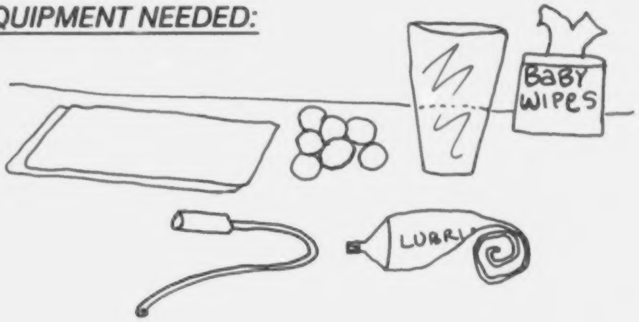
EQUIPMENT NEEDED:

Catheter

Wipes or washcloth

Container for urine

Lubricant



PROCEDURE:

1. Assemble equipment
2. Provide for privacy
3. Wash hands thoroughly with soap and hot water, rinse and dry using clean towel.
4. Without soiling your hands, position yourself on or in front of toilet, or in bed or wheelchair as required.
5. Apply lubricant to clean catheter and position container if required.
6. Females separate the labia, males pull back the foreskin.
7. Cleanse the urinary opening using a clean cloth or wipe.
8. Insert the lubricated catheter until urine flows.
9. Crede (apply pressure above pubic bone) to make sure all urine is drained from bladder.
10. Remove catheter and observe urine for color, odor, and amount before discarding.

STERILIZING CATHETERS FOR ICP

PURPOSE: To eliminate germs from catheters and avoid introducing infection into the bladder.

EQUIPMENT:

Catheters

Irrigating syringe

Washcloth or small towel

Baggies

Liquid detergent or soap

Large pot or pan with tight fitting lid

Tongs

Sterile water-soluble lubricant (if desired)

PROCEDURE:

1. Wash the catheters in hot, soapy water and rinse thoroughly. Be sure all lubricant and other particles are removed completely. Use an irrigating syringe to force water through the catheter to clean the inside.
2. Place the washcloth or towel in the bottom of the pot and put the catheters and the tongs in the pot. Add water to cover everything with at least one inch of water.
3. Cover the pot and bring to a boil. Continue to boil at a rolling boil for at least ten minutes.
4. Using the lid to keep catheters in the pot, drain the water off and allow to cool.
5. Pick up the tongs by the handle and use them to remove the catheters one at a time. Do not touch the catheters with your hands while you are doing this.
6. With the tongs, put each catheter in a clean baggie and fold or zip it shut to keep catheter clean.
7. Lubricant can be added at this time so catheters will be ready to use.
8. Store clean catheters in the refrigerator to inhibit growth of germs.

This procedure can be done in the microwave by zapping the washed catheters for 15 minutes in boiling water in an appropriate container. (Microwave-safe tray or bowl.) Do not put metal tongs in the microwave. Use plastic tongs or sterilize your metal tongs separately.

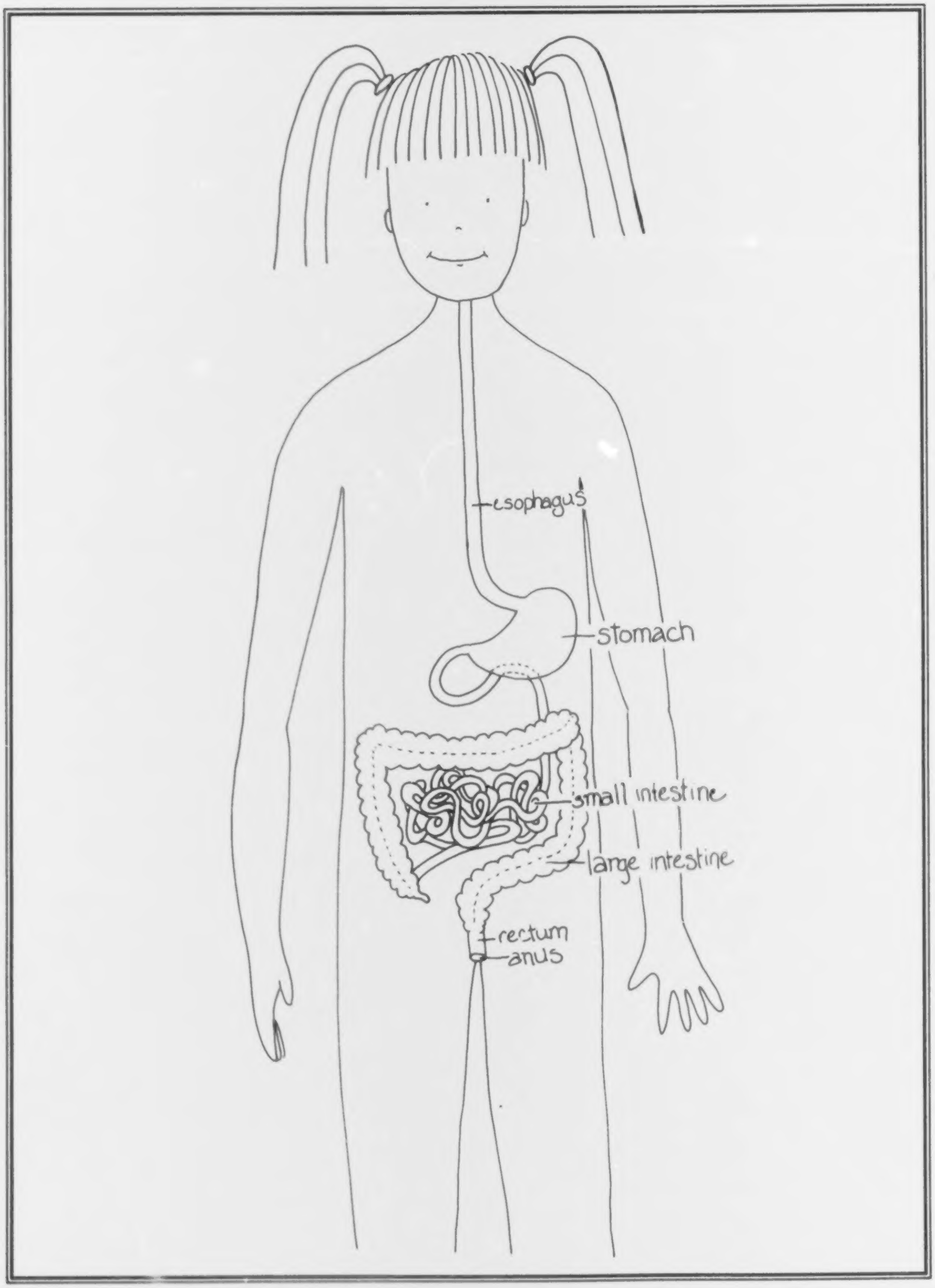
CHAPTER FIVE

BOWEL CARE

IN THIS CHAPTER YOU WILL LEARN:

- About the bowels and how they work.
- How SCI affects the bowels.
- Why you need a regular bowel program.
- About some common bowel problems and how to manage them.

THE DIGESTIVE TRACT


esophagus
stomach
small intestine
large intestine
rectum
anus

THE BOWELS AND HOW THEY WORK

The bowels, or large intestines, are part of a long tube called the digestive tract which extends from your mouth to your anus. This tube digests food and turns it into fuel for your body. Some parts of the food are not digested. These solid waste products are stored in the bowel until they are expelled from the body as "stool" or "feces."

The walls of the bowel are made of muscles which contract and relax automatically, pushing the stool down and out. The rectum is the lowest section of the bowel, where the stool collects until you are ready to move your bowels (go to the bathroom). The anus is the opening where the stool comes out. It has a donut-shaped muscle called the rectal sphincter (SFINK-ter) which, as a young child, you learn to tighten and relax in order to control your bowel movements.

HOW THE BOWELS MOVE

The process of having a bowel movement is normally controlled partly by automatic reflexes and partly by voluntary muscles. Automatic wave-like movements of the bowel wall (called PERISTALSIS) move the stool down toward the rectum at regular intervals. When some stool has collected in the rectum, you feel the need to go to the bathroom. Once on the toilet, you voluntarily relax the sphincter, push down with your abdominal muscles, and the stool comes out.

HOW SCI AFFECTS THE BOWELS

After SCI, part or all of your voluntary control over your bowels may be lost. The sensation in your rectum may be impaired, so you do not know when stool is there. Even if you have sensation, you may not be able to control your sphincter, so you cannot hold in the stool, or let it out when you want to. You may be unable to push down with your abdominal muscles, making it harder to empty your bowels.

If your injury is above T-12, you will probably have a spastic bowel. The sphincter will be tight; peristalsis will continue and expel the stool at intervals. Stimulation of the anus will cause a bowel movement by triggering increased peristalsis.

If your injury is below T-12, you will probably have a flaccid bowel. The sphincter will be relaxed and anal stimulation will have no effect. Peristalsis will move the stool down to the rectum, but it may not be strong enough to empty the bowel. The stool may need to be removed manually at regular intervals.

THE IMPORTANCE OF YOUR BOWEL PROGRAM

A bowel program is simply a plan for emptying your bowels at the same time every day (or every other day) so that you prevent bowel problems and maintain control over your bowel movements.

A regular bowel program will help you avoid two common bowel problems of people with SCI: INCONTINENCE and IMPACTION.

INCONTINENCE is having a bowel movement when you do not want one. To prevent incontinence, you will empty the bowels at a regular time every day or two. This trains the bowels so that in most cases they will move only at the desired times.

An IMPACTION is a mass of stool which gets stuck in the bowel and cannot be expelled by ordinary methods. This can happen if you allow stool to stay too long in the rectum. The mass of stool becomes bigger and harder until it will not come out. This can make you seriously ill.

WHEN TO DO THE BOWEL PROGRAM

Timing is very important. The best time to do a bowel program is one half hour after a large meal. Eating causes the bowel to become more active, with increased peristalsis and often an urge to move the bowels. This is called the GASTRO-COLIC REFLEX.

If your injury is Lower Motor Neuron, you will need to check your bowel after every meal. This will avoid accidents and clear the rectum so that the stool will keep moving down and out. Some people also do a bowel check before bedtime.

If your injury is Upper Motor Neuron, you will probably only need to do your program once a day, or once every other day. Whether to do your bowel program in the morning or evening is a decision you will make based on several factors:

- Did you have a regular time for bowel movements before your injury? Try to maintain that schedule if you can.
- What is your current school or work schedule? The bowel program should be scheduled to accomodate your other activities.
- Do you need assistance with the program? You will need to schedule it when assistance is available.
- How long does your bowel program usually take? It can be anywhere from five minutes to over an hour. Avoid rushing to prevent accidents.

Once you establish a good time, do your program at the same time (within 1/2 hour) every day. It may take up to several weeks to achieve regularity; once the program is well-established, you should not have bowel movements at other times. If you find after a trial period it is not working, or if you want to change because your schedule changes, it can be done, but it may take a while to make the transition. You should expect and provide for possible accidents until the new schedule is well established.

While you are in the hospital, you will be given instructions on how to do your bowel program or how to instruct a helper to do it. Be sure to change the instructions if the program changes.

COMMON BOWEL PROBLEMS

CONSTIPATION

CONSTIPATION is difficulty moving your bowels because of a hard, dry stool. It can cause many problems, such as muscle spasms, headaches, trouble sleeping, grouchiness, poor appetite, nausea, vomiting, hemorrhoids, or even dysreflexia. *(See Chapter 9 on Complications for an explanation of dysreflexia, a medical emergency.)* If allowed to persist, constipation can become impaction, in which a hard mass of stool gets stuck in the bowel and cannot be removed by normal means.

Measures to prevent or treat constipation:

- Take adequate fluids and eat a well-balanced diet with plenty of fiber. (Whole grains, fruits and vegetables have the most fiber.)
- Avoid or limit foods which tend to "bind" the bowels, such as apples, cheese, popcorn, and refined grains such as white rice or white bread.
- Follow a regular bowel program and make sure your bowels empty as completely as possible. Take stool softeners as prescribed by your doctor if needed.
- Be aware of how often your bowels move, and do not allow more than two days to go by without a movement. Try to stimulate your bowels to move, and if you cannot, tell your doctor. A laxative or enema may be prescribed.

DIARRHEA

Loose, watery, frequent or explosive stools are called DIARRHEA. There are many causes, ranging from stress to an intestinal infection. Occasional mild diarrhea is usually caused by changes in your diet or fluid intake.

Measures to treat a diarrhea stool:

- Stop taking any stool softeners or laxatives you usually take.
- Cut down on fruit and fruit juices. Cut out all alcoholic beverages and caffeine until your stool is back to normal.
- Eat cheese, popcorn, rice or apples, which may help "bind" the stool.
- Drink plenty of fluids to replace the water lost through the stool.
- If diarrhea persists more than 24 hours, notify your doctor. You can become seriously dehydrated (dried out) and lose vital substances with prolonged diarrhea.

DIARRHEA OR IMPACTION?

A scant, watery stool can sometimes indicate impaction, as some loose stool leaks around the hardened mass of stool in the bowel. This can generally be distinguished from diarrhea by the relatively small amount. If you have diarrhea after not being able to move your bowels for a while, suspect impaction and notify your doctor. This condition requires medical treatment.

HEMORRHOIDS

HEMORRHOIDS are swollen blood vessels surrounding the anus. You may or may not be able to see them, depending on whether they are inside or outside the sphincter. Hemorrhoids are usually caused by hard stool irritating the anus, or by rough handling of the delicate anal tissue.

If you do not have feeling in your anal area, the first sign of a hemorrhoid may be bright red blood in your stool or in the toilet. If you or your helper notices a swelling, or a bloody stool, you should take measures to reduce the irritation and to prevent further damage.

Measures to prevent or reduce hemorrhoids:

- Keep the stool soft by taking plenty of fluids and high fiber foods, and using a stool softener or laxative if prescribed by your doctor.
- Use plenty of lubricant during your bowel program and handle the anal area very gently. Keep fingernails trim and smooth; replace rough or broken anal stimulators.
- If you do have hemorrhoids, ask your doctor or nurse about using one of the over-the-counter ointments available at the pharmacy.
- If there is a lot of bleeding, tell your doctor. You may need medical treatment.

BOWEL CHECKLIST

Briefly describe the structure and function of the bowel.

How has YOUR bowel been affected by SCI?

What are the most important reasons for doing a bowel program?

What are the meanings of these words: Incontinence, diarrhea, constipation, impaction, peristalsis?

Why do we try to schedule a bowel program after a meal whenever possible?

How often and at what time of day do you do YOUR bowel program?

What supplies do you need for your bowel program?

Demonstrate and/or talk the nurse through your bowel program, as if she or he had never done it before. You will need to be clear about each step so that you can complete it at home by yourself, or instruct a helper to do it.

What are hemorrhoids? What causes them? How can you prevent or minimize them?

UPPER MOTOR NEURON BOWEL TRAINING PROGRAM (BTP)

PURPOSE: To empty the bowel at a regular time each day, in order to avoid incontinence of stool or impaction of stool.

EQUIPMENT NEEDED:

Toilet tissue

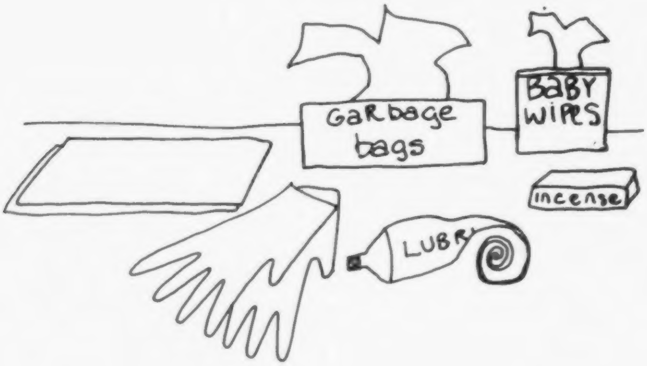
Water-soluble lubricant

Suppository (if needed)

Adaptive equipment (if needed)

Protective sheet (or plastic bag) if performing in bed

Rubber gloves (lightweight kitchen gloves can be washed and reused)



PROCEDURE:

1. Position yourself on the commode chair or toilet; or, if in bed, on your left side.
2. If in bed, place a protective sheet or plastic bag under buttocks. You may use a paper towel or tissue to collect the stool.
3. If suppository is used: put some water-soluble lubricant on the suppository and with a gloved hand insert the suppository into the rectum as high up as you can reach. Be sure the suppository is in contact with the bowel wall, not embedded in stool. Allow the suppository to melt at least 10 - 15 minutes. If no suppository is used, go on to the next step.
4. Perform digital stimulation: Insert a well lubricated gloved finger (or anal stimulator if used) into the anus about one inch, move the finger in a circle to stretch open the anus. Continue to stimulate this way for 3-5 minutes if necessary until the stool moves down and out of the anus. If there are no results after 5 minutes, rest for 10 minutes and try again.
5. If results are obtained, try again in 10 - 15 minutes until there are no more results.
6. If no results after one or 1 1/2 hours, discontinue the procedure and try again the next day.
7. Cleanse the anal area and discard waste.

Hints

- Perform BTP after a meal for best results.
- Drink something hot to stimulate bowels to move.
- Keep a closed plastic bag handy to deposit waste.

LOWER MOTOR NEURON BOWEL TRAINING PROGRAM (BTP)

PURPOSE: To empty the lower bowel of stool at regular intervals, in order to avoid incontinence or impaction.

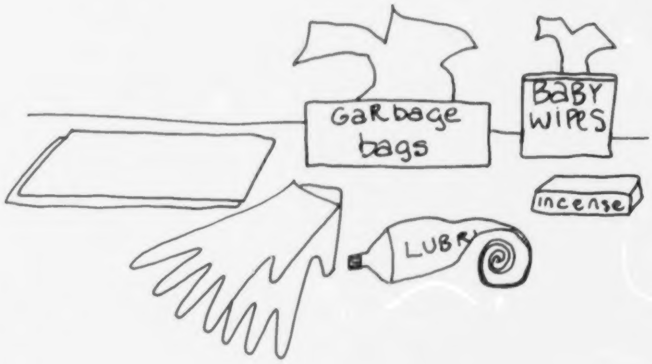
EQUIPMENT NEEDED:

Water-soluble lubricant

Rubber glove (lightweight kitchen glove can be washed and reused)

Protective sheet (or plastic bag) if performing in bed

Toilet tissue or paper towel



PROCEDURE:

1. After each meal, position yourself on the toilet or in bed on your left side.
2. Using a lubricated, gloved finger, remove as much stool from the lower rectum as possible.
3. Cleanse the anal area and discard waste.

CHAPTER SIX

NUTRITION

IN THIS CHAPTER YOU WILL LEARN:

- The importance of a balanced diet after SCI.
- About the major food groups and a nutritious food plan.
- How to avoid unwanted weight gain after SCI.
- Which foods will help you stay healthy.
- Which foods you should limit or avoid.

FOOD AND NUTRITION

Food provides you with NUTRIENTS - the substances your body needs to grow and stay healthy. Good nutrition means eating wholesome foods that provide you with all the nutrients you need, and not eating too much of the foods that are useless or harmful to your health. In this section you will learn how to choose wholesome foods and create a healthy eating plan for yourself.

WHY STUDY NUTRITION?

Before your injury, you may not have thought much about the nutritive value of the foods you ate. Most active young people can eat just about anything and stay slim and healthy. But because you are not moving around as much, you are more prone to certain diseases, bowel problems and weight gain. Eating nutritious, well-balanced meals can make a big difference in whether you remain healthy or not.

MILK
OATS
pasta

THE BASIC FOOD GROUPS

In order to make it easier to choose balanced meals, nutritionists have arranged all foods into basic food groups. By eating the proper number of servings from each food group every day, you will get the right amount of all the important nutrients. The chart below shows you how many servings of each food group you should include in each day's menu. The serving size of each food is also shown so you will know how much of each food you should eat. On the following pages you will find an explanation of each of the food groups and what nutrients they provide.

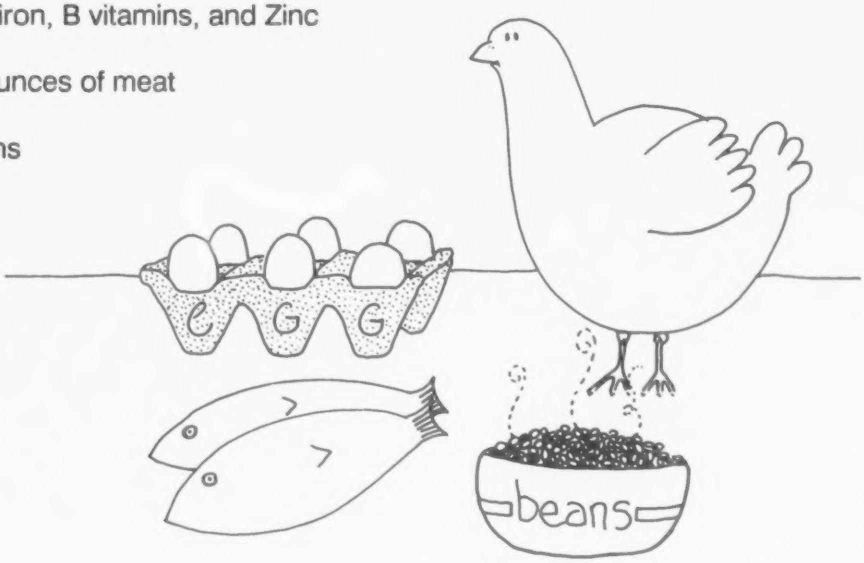
PROTEIN FOODS - 2 servings/day

Nutrients: Protein, iron, B vitamins, and Zinc

Serving size: 2-3 ounces of meat

1 cup cooked beans

1 egg



Lean meats, poultry, fish, eggs, beans, lentils, sprouts, nuts and seeds are all high in protein. Protein is a nutrient needed by every tissue in your body to grow and rebuild itself. Most Americans eat plenty of protein, often too much. It is best to eat a small amount every day, since unused protein breaks down into other substances, including fat and uric acid, which are harmful to your body. Also, fatty meats and eggs are high in saturated fats and cholesterol, which may contribute to heart disease and other problems. It is best to get most of your protein from skinned poultry, fish, beans and other vegetable sources, and to eat no more than three eggs a week.

STARCHES 4 servings/day

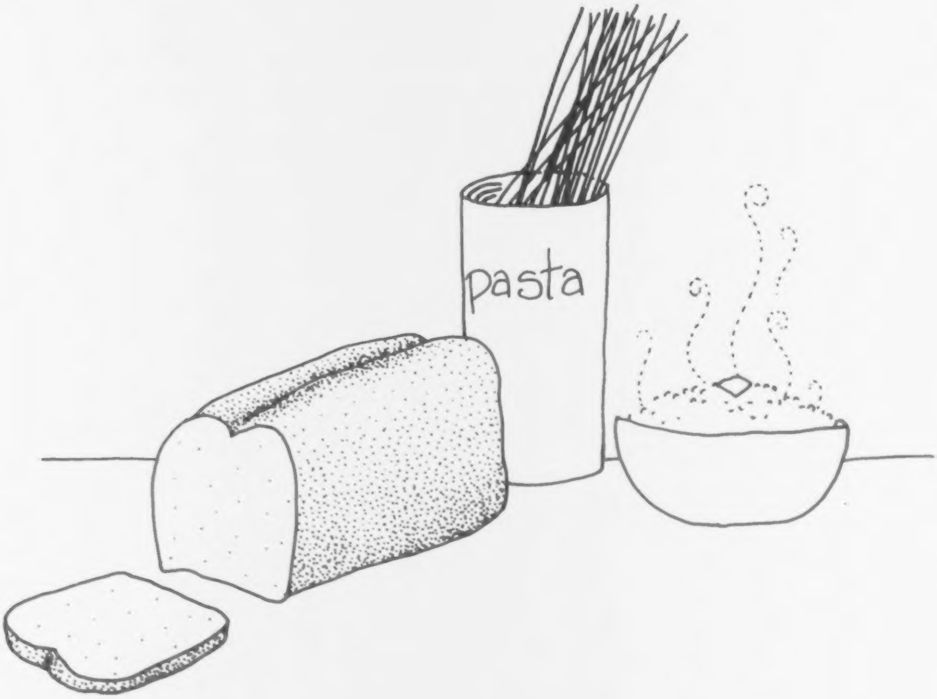
Nutrients: fiber, calories, B vitamins, and iron

Serving size: 1 slice of bread

1 ounce dry cereal

1/2 cup cooked grain, cereal or noodles

Bread, cereal, rice, potatoes, corn, crackers, spaghetti, noodles, tortillas and any other foods made from grain or flour are high in starch, or "complex carbohydrates." These foods give you the energy you need for movement, warmth, and internal functions. In their whole, natural state, grains also contain valuable vitamins, minerals and fiber, which are important for good health. This is why it is recommended that you eat whole grain products instead of refined (white) products as much as possible.

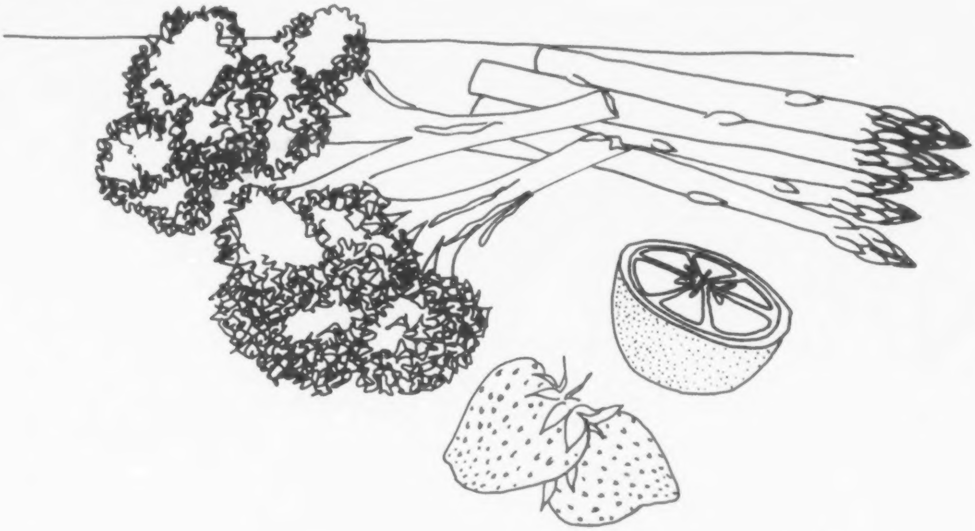


FRUITS & VEGETABLES 4 or more servings/day

Nutrients: Vitamins A, B's, C, fiber, iron and other minerals

Serving size: 1/2 to 1 cup cooked

or 1 piece of fruit



Fresh, canned, frozen or dried, fruits and vegetables contain vitamins, minerals and fiber, as well as varying amounts of starches and sugars. Vitamins and minerals are substances used in the chemical processes of your body. Fiber is the indigestible part of the plant which helps keep your bowel healthy and also draws excess fats out of the body. It is best to eat fresh, whole fruits and vegetables whenever possible because they have more nutrients than processed foods. For the best nutrition, eat at least one leafy green vegetable, such as spinach, greens or cabbage each day. Eat an orange vegetable such as carrot, pumpkin or sweet potato two or three times a week.

Vegetables are so important for your digestion and health that you should find ways to fit them into your meals even if you do not particularly care for them. Pumpkin pie, vegetable soup, carrot and raisin salad, spinach quiche, tacos with tomatoes and peppers, or celery in your tuna salad are just a few examples of how vegetables can be included in your meals. You might try them baked in a crust or fried in batter like fritters - but try them!

One or more fruits can be eaten each day. Sometimes too much fruit can cause diarrhea. If you have trouble with loose bowels, try limiting your fruits or fruit juices to one or two servings a day, or try a different kind of fruit. If constipation is a problem, fruit can often help make your bowels move more smoothly.

DAIRY PRODUCTS 2 to 4 servings/day

Nutrients: Calcium, riboflavin, protein, phosphorus

Serving size: 8 ounces milk or yogurt

1 ounce (1 slice) cheese

Milk, cheese, yogurt, buttermilk and kefir (a cultured milk drink) are all high in calcium, protein and other nutrients. Calcium is good for strong bones and teeth, as well as for many chemical processes in the body. Dairy products combined with vegetable protein foods such as beans or lentils increase the protein value of these foods. Dairy products can be a valuable part of the diet.

However, some people should not eat too many dairy foods. After SCI, your bones may lose some of their mass, and the lost calcium may contribute to stones in the kidneys or bladder. Check with your doctor about whether you need to limit your intake of dairy products. Whole milk products also contain a lot of fat, which is high in calories and cholesterol. It is best to use non-fat or low-fat dairy products whenever possible, such as skim milk, cottage cheese, and non-fat yogurt.

MILK ♥♥♥
YOGURT

OTHERS: SUGARS, SALT, FATS AND OILS

Nutrients: calories, essential fatty acids

The last group includes all the miscellaneous oils, fats, sweets, condiments, and other foods we eat mostly for flavor and enjoyment. These foods are often high in calories but low in nutrients.

SUGARS

Sugar comes in many forms. Whether white or brown granulated sugar, honey, molasses, syrup or malt, it is a refined product with little or no food value except calories. It is better if you can limit your intake of foods high in sugar, such as cookies, candy, pastries, cake, pie, ice cream, soft drinks and other sweets as much as possible, substituting natural sweets such as fruits, which have more food value.

SALT

Salt is a mineral which serves some very important functions in your body. But after SCI, too much salt can cause edema (swelling) and kidney problems. Potato and corn chips, candy, salt-cured lunch meats, fast food meals, pizza, canned soups, cheese and many other processed, frozen and canned foods have large amounts of salt and should be eaten only once in a while. Try to avoid the habit of putting extra salt on food at the table; after a short while, the food will taste fine without it.

FATS AND OILS

This group includes vegetable oils, lard, butter, margarine, shortening, and foods high in fat such as chocolate and many candies, mayonnaise, salad dressings, sauces, olives, salami, bacon and other fatty meats.

The average American diet is overly high in fats and oils. Only about one tablespoon a day is needed to provide the essential fatty acids required for good health. Eating too much fat may contribute to overweight, digestive problems, and heart disease. Fats have also been linked with certain cancers.

It is best to eat fried foods, pastries, candy and salad dressings only in small amounts and as occasional treats. Eat low-fat or non-fat dairy products. Trim the visible fat from meats and limit eggs, butter and oils.

WATER

Water is one of the most important nutrients. Digestion, urination, skin tone, blood pressure, and all body processes require water in order to work properly. If you get dehydrated (too dry) you can become seriously ill quite quickly. For some people, too much water can also cause problems. Find out how much liquid you should drink and get in the habit of drinking at regular times throughout the day.

Water is also found in milk, juice, tea, coffee, sodas and other sweet drinks, and in foods such as soup, watermelon, jello and ice cream. If your fluids are restricted, these should all be counted in your total liquid for the day.

GENERAL DIETARY RECOMMENDATIONS

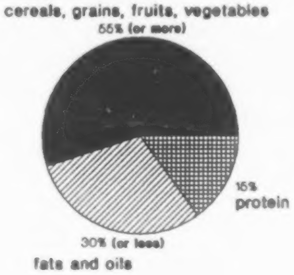
Research has shown that the healthiest food plan is:

LOW in fats, salt and refined sugars,

with LIMITED amounts of eggs, red meat, and dairy

and HIGH in whole grains, fruits and vegetables.

Recommended Percentage of
Calories from each food group



Eat a variety of foods from the basic food groups as the foundation of your food plan. This ensures that over time you will get all the needed nutrients in good balance. Use "extra" foods such as sweets in small amounts only to enhance - but never to replace - nutritious meals.

Adjust the amount of food you eat to maintain your ideal weight. If you want to lose weight, cut back on the "extras" you eat and limit yourself to the recommended number of servings from each food group.

PROBLEMS RELATED TO DIGESTION AND NUTRITION

OVERWEIGHT

Just as a car gets its energy from gasoline, your body gets energy from the food you eat. The more active you are, the more food energy you use. If you take in more food than you can use, the extra is stored as fat, and you gain weight. If you are less active now than before your injury, you need to take in less food or you may become overweight.

Overweight is unhealthy for everyone, but after SCI it can pose some special problems. Extra weight will put more pressure on your pressure points. It will make it harder for you to transfer, or for others to assist you. It will further impair your slowed circulation. It will be very difficult for you to lose the weight once you gain it, since your activity is limited by your injury.

You may lose weight right after your injury, because your appetite may be poor, and muscles that are not being used tend to get smaller. But when you get home, your appetite may improve as you fall into your old eating patterns. If you find your appetite calls for more food than you now need, it is best to start on a reasonable, moderate eating plan that will keep you as close to your ideal weight as possible.

Start by substituting low-calorie foods for some of the high-calorie foods you were eating before. If you are unfamiliar with the calorie content of foods, get a "calorie counter" book and look up the foods you eat most often. Limit or eliminate fried foods, rich sauces and gravies, extra desserts and snacks. Stick with your basic food groups and use fruits or vegetables for snacks. Use non-fat dairy products and diet soft drinks or herb tea instead of drinks high in sugar.

Weigh yourself once a week or so and if you notice you are gaining weight, do something about it immediately. Do not wait until you are ten or fifteen pounds overweight to cut back. By then it will be much harder to lose it.

UNDERWEIGHT

Underweight is sometimes a problem if you have lost a lot of muscle mass and do not have any padding. It may be comforting to know that as long as you are getting enough nutrients to stay healthy, it is better to be a LITTLE underweight than to be overweight. However, it is important to use extra padding on your pressure points to protect your skin.

If your appetite is poor, and you are not eating enough nutritious food, you can lose energy, become depressed, and be more prone to disease. Make a point of eating high quality foods such as lean meat, poultry and fish, whole grains, fresh fruits and vegetables. Avoid junk foods, such as chips, candy and carbonated drinks, which will satisfy your appetite without nourishing you. Substitute snacks rich in nutrition and calories such as custard, milk shakes, dried fruits and nuts. Eat several times a day to increase your total calories. Talk to your doctor about any prolonged loss of appetite. This may be a sign of an underlying physical or emotional problem.

AVERAGE WEIGHT CHARTS FOR BOYS AND GIRLS

	BOYS		GIRLS	
AGE	HEIGHT (INCHES)	WEIGHT (POUNDS)	HEIGHT (INCHES)	WEIGHT (POUNDS)
5	43	41	42	39
6	46	45	45	44
7	48	50	48	48
8	50	56	50	55
9	52	62	52	63
10	54	69	55	72
11	56	78	57	82
12	59	88	60	93
13	61	99	62	102
14	64	112	63	110
15	66	125	63	118
16	68	137	64	124
17	69¼	146	64¼	125
18	69½	152	64½	124

To determine your proper weight, find your age and note the corresponding height and weight. If you are shorter than average for your age, your proper weight will be less than the average weight shown; if you are taller, your proper weight will be more.

Remember these are averages. Normal weight for growing children and teens may vary up to 10 pounds lower or higher than the average, since not everyone grows at the same rate.

BEST COPY AVAILABLE

ULCERS

An ulcer is a sore which develops inside the digestive tract as a result of irritation. The most frequent cause of ulcers is stress, which increases the stomach acid in some people. The ulcer can cause pain, and if not treated, it may bleed. It can eventually make a hole in the stomach or intestinal wall, which is very serious.

As you know, it is very stressful to be injured and to stay in the hospital for long periods, so it is possible you could develop an ulcer. You should be aware of the early warning signs, which are pain and indigestion. It is important to prevent stomach irritation and to watch for any signs of bleeding from the digestive tract.

Eating a bland, soft diet, without too much salt or spices, will help reduce irritation to your stomach. It also helps to eat several small meals a day rather than two or three large ones. If you tend to get worried and tense easily, it is wise to learn some methods for relaxing and letting go of tension. It is best not to eat when you are very angry, tired or upset; it has been shown that emotional upset and fatique interfere with digestion.

Be aware of the color and appearance of your stool. If it becomes black and tarry (sticky) this may mean there is bleeding somewhere in your digestive tract. Report this to your doctor immediately. If you have recurrent vomiting, or if you vomit blood, this should also be reported right away.

NUTRITION CHECKLIST

Why is it important to take as much fluid as you are allowed each day?

What do we mean by a "balanced diet"?

What are the basic food groups and describe an average serving from each group.

What is fiber and why is it good for you?

What foods should be avoided or limited for optimum health?

What is an ulcer and what are the signs of an ulcer?

Why is it important to avoid getting overweight after SCI?

What is your ideal weight and how do you plan to maintain it?

Which food group should you limit first if you want to lose weight?

If you are underweight, what special precautions should you take to protect your skin and your health?

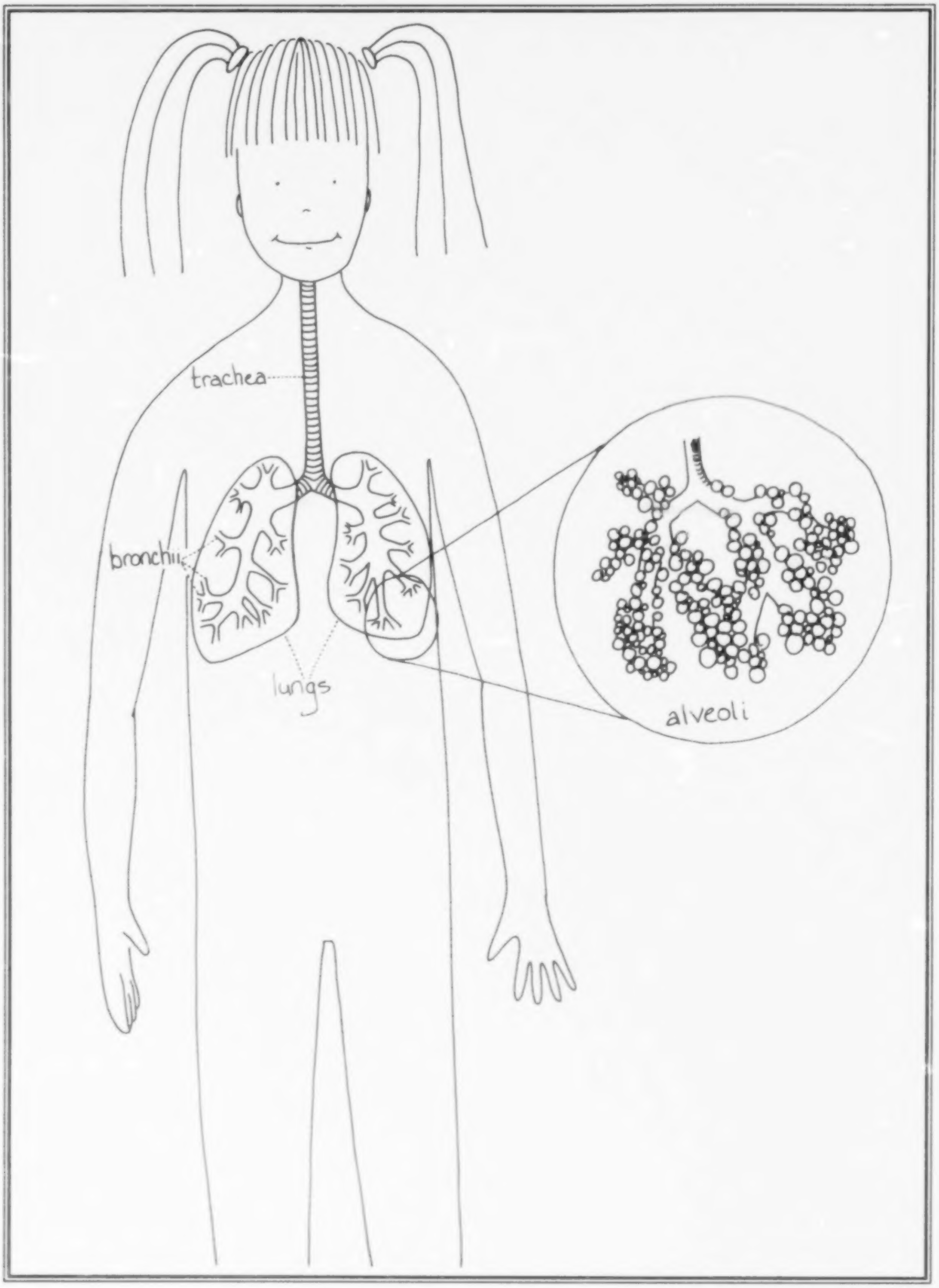
CHAPTER SEVEN

THE RESPIRATORY SYSTEM

IN THIS CHAPTER YOU WILL LEARN:

- How your respiratory system works.
- How SCI affects your breathing.
- About the breathing treatments you may have.
- How you can keep your lungs healthy.
- The signs of a respiratory infection.

THE RESPIRATORY SYSTEM

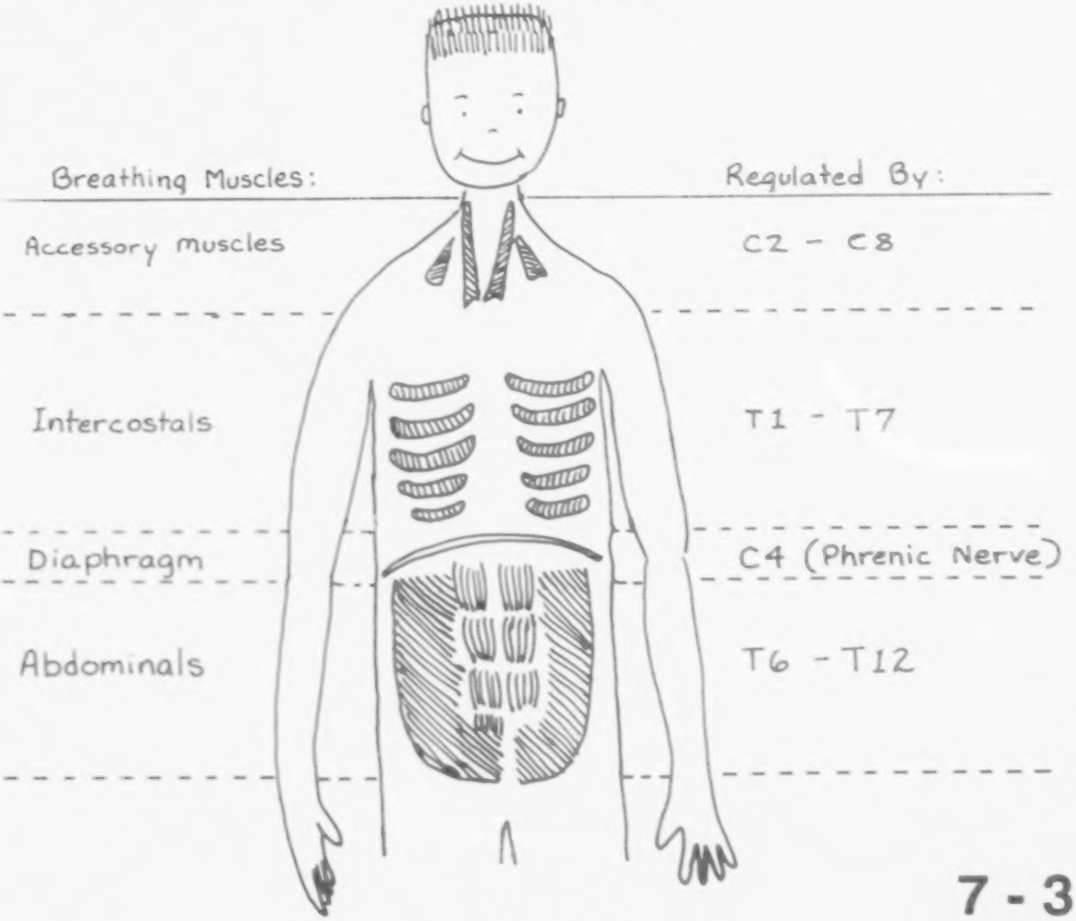

trachea
bronchii
lungs
alveoli

HOW YOUR RESPIRATORY SYSTEM WORKS

The respiratory (breathing) system includes the lungs and all the passages which bring air into and out of the body. The lungs are made up of thousands of tiny air sacs called alveoli, and are lined with a moist membrane similar to the inside of your mouth. A network of blood vessels in the lungs collects oxygen from the air and distributes it throughout the body. Your body needs a constant supply of oxygen to stay alive.

There are several sets of muscles which contract and expand the chest to make breathing and coughing possible. The diaphragm is a large sheet of muscle just below the lungs which contracts every time you breathe in, opening up the chest to draw air in. The intercostal muscles between your ribs contract every time you breathe out, closing up the chest and pushing the used air out. Your abdominal (stomach) muscles are also used in breathing, especially when you cough. Some or all of these muscles may be affected by SCI, depending on the level of your injury.

The accessory muscles in your neck and shoulders are not normally important in breathing. But a person with a high injury will use these muscles to help compensate for the loss of intercostal and abdominal muscles.



Breathing Muscles:	Regulated By:
Accessory muscles	C2 - C8
Intercostals	T1 - T7
Diaphragm	C4 (Phrenic Nerve)
Abdominals	T6 - T12

HOW SCI AFFECTS BREATHING

If your injury is above T - 12, your breathing or coughing muscles may be weakened. The chart shows the effect on your breathing of each level of injury.

Level of Injury	Useful Muscles				Effect on Breathing
	Accessories	Diaphragm	Intercostals	Abdominals	
C4 and above	partial	no	no	no	mechanical ventilation required
C5 - C8	yes	yes	no	no	shallow breathing, no cough, paradoxical breathing. Accessory muscles needed
C8 - T6	yes	yes	no or partial	no	shallow breathing, cough weak or absent
T6 - T12	yes	yes	yes	no or partial	weak cough
Below T12	yes	yes	yes	yes	no effect on breathing

A common problem involves the secretions (fluids) which coat the inside of the lungs and all the air passages. Normally, your daily activity and coughing keep these secretions moving up and out of the lungs. After SCI, your immobility and weakened cough may allow the secretions to build up. They tend to block the air passages and become a breeding ground for infection.

If you have a problem with secretions, you will need to learn how to do assisted coughing ("quad cough") and/or some other ways to clear your lungs. How much of this will be necessary depends on the level of your injury and on the amount of secretions you have. Even if you do not usually need respiratory assistance, you may need it when you have a cold, flu or bronchitis.

Robert Weygandt

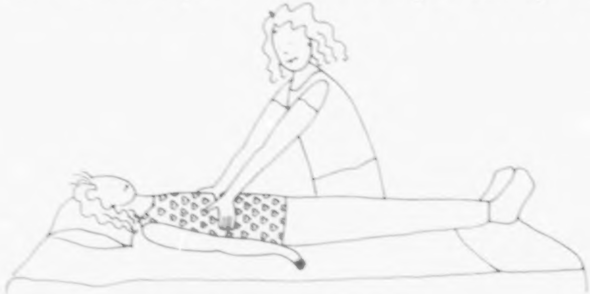
At 16, Rob was hit by a truck and came to Shriners for rehab with a C-6 spinal cord injury.

Rob had some respiratory problems after he went home. "I got a cold that turned into pneumonia. I had a lot of trouble breathing. I went to the doctor and got antibiotics. But I couldn't cough.

"I figured out I could do a "quad cough" on myself by leaning forward in my chair and putting pressure on my diaphragm with my arms. Then I was able to cough up the secretions. This helped my breathing a lot."

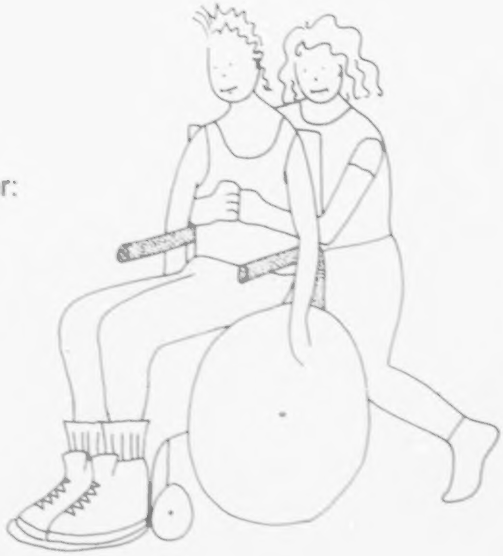
QUAD COUGH

Assisted coughing, or "quad cough," simply means having another person help you breathe out forcefully in order to clear your air passages better. It is performed very much like the "Heimlich Maneuver," used to save people who are choking. The person helping you stands in front of or behind you if you are sitting, or over you if you are lying down, and pushes up on your diaphragm while you cough or breathe out as hard as you can. This is done until you can bring up any extra mucus or secretions into your throat where you can spit them out or swallow them.



When doing "quad cough" be sure to tell your helper:

- Avoid quad cough right after eating - you might throw up!
- Avoid pushing on the ribs or the chest bone - this can injure you.
- Push only when you are breathing OUT.

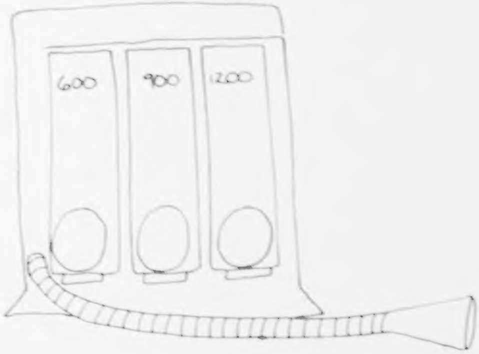


PERCUSSION AND POSTURAL DRAINAGE

If the quad cough does not work to loosen and bring up secretions, PERCUSSION AND DRAINAGE is very helpful and effective. You are placed in a series of positions which allow gravity to help drain the secretions. Your caregiver taps firmly on your chest with cupped hands. This loosens the secretions from the lining of the air passages. The secretions work their way up to your throat, where they can be spit out or suctioned out if you cannot cough them up yourself.

If you need this type of treatment, a respiratory therapist or nurse will teach you and your helpers how to do it. This can then be done at home whenever it is needed to keep your breathing clear.

BREATHING TREATMENTS



You may have special breathing treatments using an Intermittent Positive Pressure Breathing machine (IPPB) which will expand your lungs and help loosen secretions. You may also be given a small "breathing exercise machine" called an INCENTIVE SPIROMETER which will help you strengthen your breathing muscles. Your breathing exercises will become part of your daily routine and will help prevent lung infections.

HOW TO KEEP YOUR LUNGS HEALTHY

Like most diseases, respiratory infections are easier to prevent than to cure. By getting into good habits, you can avoid serious illnesses such as pneumonia and improve your overall health and well-being.

1 DO NOT SMOKE, AND DO NOT ALLOW OTHERS TO SMOKE AROUND YOU.

2. DRINK PLENTY OF FLUIDS (WITHIN YOUR FLUID LIMITS).

3. AVOID PEOPLE WITH COLDS OR COUGHS.

4. USE YOUR SPIROMETER OR TAKE SEVERAL DEEP BREATHS SEVERAL TIMES A DAY TO FULLY EXPAND YOUR LUNGS AND STRENGTHEN YOUR BREATHING MUSCLES.

5. IF YOU DO GET A COLD:

   - GET UP IN YOUR CHAIR, DO NOT STAY IN BED.
   - DO FREQUENT QUAD COUGHS OR PERCUSSION AND DRAINAGE AS NEEDED TO KEEP SECRETIONS CLEARED.

6. SEE A DOCTOR IF YOU HAVE A FEVER, SHORTNESS OF BREATH, THICK YELLOW OR GREEN SECRETIONS, OR CHEST PAIN. THESE ARE SIGNS OF A LUNG INFECTION.

RESPIRATORY CHECK LIST

What are the parts of the respiratory system and what do they do?

How has YOUR respiratory system been affected by SCI?

What measures have you been taught to keep your lungs healthy?

Describe how you would instruct someone to assist you with a quad cough, percussion and drainage, or use of the spirometer.

How can you prevent respiratory problems and infections?

When you have a cold you should stay in bed. (True or False)

What are the signs of a lung infection?

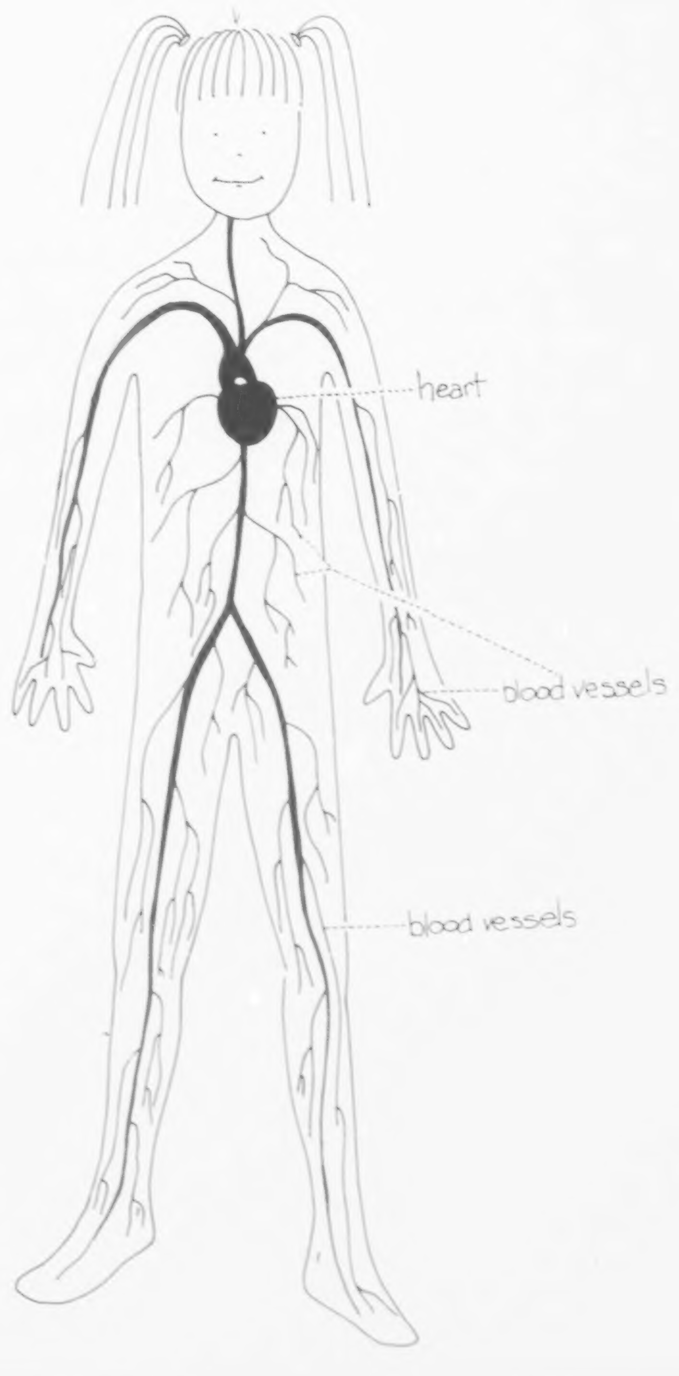
CHAPTER EIGHT

CIRCULATION

IN THIS CHAPTER YOU WILL LEARN:

- How your circulatory system works.
- How SCI affects the circulation.
- What to do about some common circulatory problems.
- Three recommendations for healthy circulation.

THE CIRCULATORY SYSTEM


heart
blood vessels
blood vessels

HOW YOUR CIRCULATORY SYSTEM WORKS

The circulatory system is made up of the heart, blood vessels and blood. It serves to carry oxygen and nutrients to every part of your body, and to remove the waste products of body processes.

The heart is a muscular organ the size of your fist which pumps blood through the blood vessels. The blood vessels form a network of tubes which carry the blood throughout your body. The blood itself includes many different substances needed for life. A continuous supply of circulating blood is necessary to keep your body alive and working.

HOW SCI AFFECTS THE CIRCULATION

Normally, the blood vessels are flexible. They get bigger or smaller in diameter to help your body adjust to changes in temperature and other changes in your environment. After SCI, the blood vessels below the level of injury are usually permanently expanded or relaxed. This slows the circulation of blood and lowers the blood pressure.

Certain problems can result from these changes. You can avoid many of these by taking good care of yourself. If you have trouble controlling any of the conditions described here, tell your doctor. He or she will want to treat the problem before it becomes serious.

SOME COMMON CIRCULATION PROBLEMS AFTER SCI

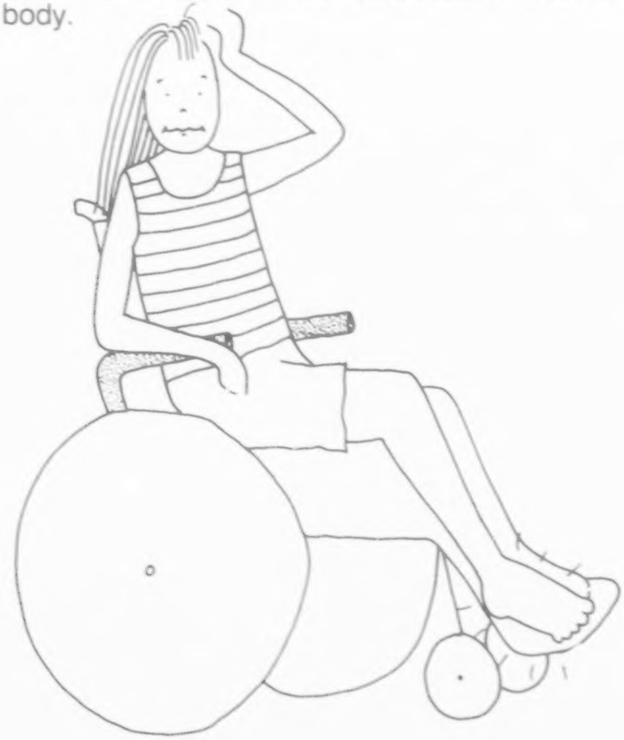
SKIN CHANGES

The most common problem caused by poor circulation is a decreased flow of blood to the skin. Good skin care and frequent weight shifts will help protect your skin. *(Please read Chapter 3 on Skin for more about the importance of skin care.)*

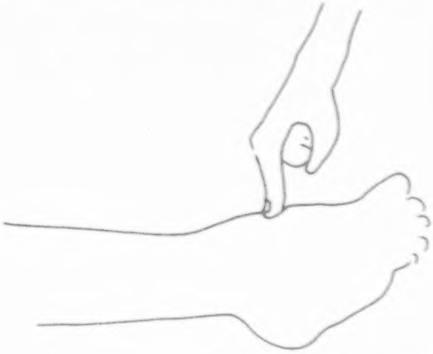
SWELLING (EDEMA)

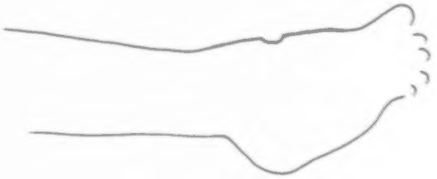
Extra water in your body may settle in your feet and legs, causing swelling and puffiness. Mild edema is not a serious problem, but it should be controlled because it can affect the skin. Mild edema can often be reduced by taking these simple steps:

- Several times a day, raise your feet and legs with a pillow or, if in your wheelchair, put them up on a chair or sofa. Gravity will help the fluid drain from your feet.
- Use elastic (TED) stockings. These compress the feet and lower legs gently and evenly, preventing the fluid from settling there. If you do not have elastic stockings, ask your doctor about prescribing them.
- Reduce the amount of salt in your food as much as possible. Too much salt holds fluid in the body.

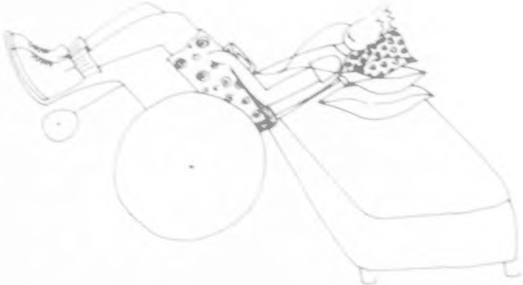


PITTING EDEMA, when a finger pressed into the skin leaves a dent, should be reported to your doctor.





POSTURAL HYPOTENSION



If you have a high injury, you may get dizzy or nauseated when you lie down or sit up. You may even feel faint or pass out. This is due to "postural hypotension," which is a drop in your blood pressure with a change of position. Not enough blood is getting to your brain. If this problem is severe, tell your doctor.

For mild or occasional dizziness, it may help to raise or lower your head very slowly, giving the blood time to make the shift gradually. Try leaning forward or back so your head is lower; take some deep breaths. Using elastic stockings and/or an abdominal binder may help prevent or reduce this problem. Be sure to drink enough fluids; this will keep your blood volume up and may help prevent hypotension.

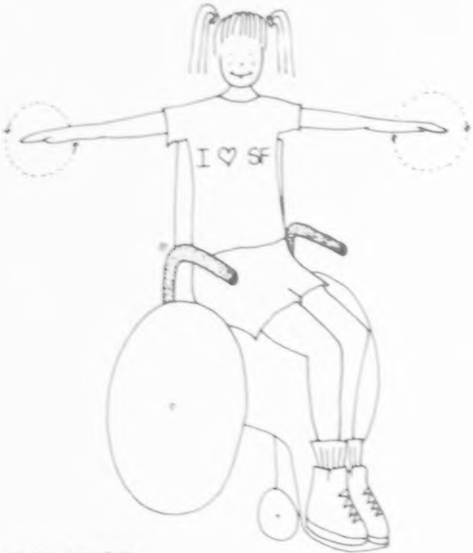
OTHER COMPLICATIONS

There are other, more serious complications which occasionally occur after SCI. Please read Chapter 9 on Complications for a thorough explanation of Dysreflexia, Thrombophlebitis, and Kidney Problems.

THREE HINTS FOR CIRCULATORY HEALTH

BE ACTIVE

Whatever you can move, move it. Even limited movement will have a good effect on your circulation. Range of motion exercises also improve circulation and joint flexibility. Every day, have someone help you move any parts of your body you cannot move on your own.



MAINTAIN A GOOD FLUID BALANCE

Drink as much fluid as you are allowed and drink at regular times throughout the day. This will help keep your blood pressure up. Empty your bladder at regular intervals to prevent dysreflexia. If you drink alcoholic beverages, drink very limited amounts. Alcohol draws fluid out of your body and can make you dehydrated.

EAT WELL FOR HEALTHY CIRCULATION

Research has shown that a diet low in salt, fat and cholesterol can help prevent "hardening" (sclerosis) of the blood vessels and reduce the chance of heart attack and stroke. It makes sense to take good care of your blood vessels if you want to give your body the best chance for health. *(Please read Chapter 6 on Nutrition for more about a healthy diet.)*

CIRCULATION CHECKLIST

Briefly describe the circulatory system and how it works.

How has SCI affected your circulation?

How does your slower circulation and lower blood pressure affect your skin?

If you use TED hose or a binder, what is their purpose?

What steps can you take to reduce swelling in your feet or legs if that becomes a problem?

Why is it important to your circulation to take plenty of fluid?

How does activity affect your circulation?

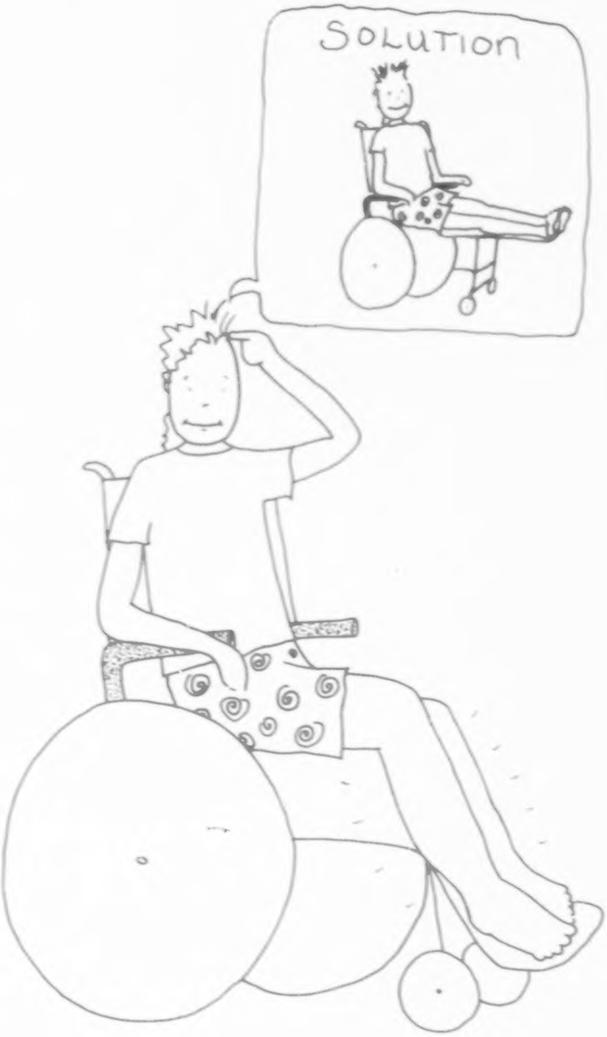
How does drinking alcoholic beverages affect your circulation?

CHAPTER NINE

COMPLICATIONS

IN THIS CHAPTER YOU WILL LEARN:

- About some common complications of SCI.
- How to recognize, prevent and treat them.

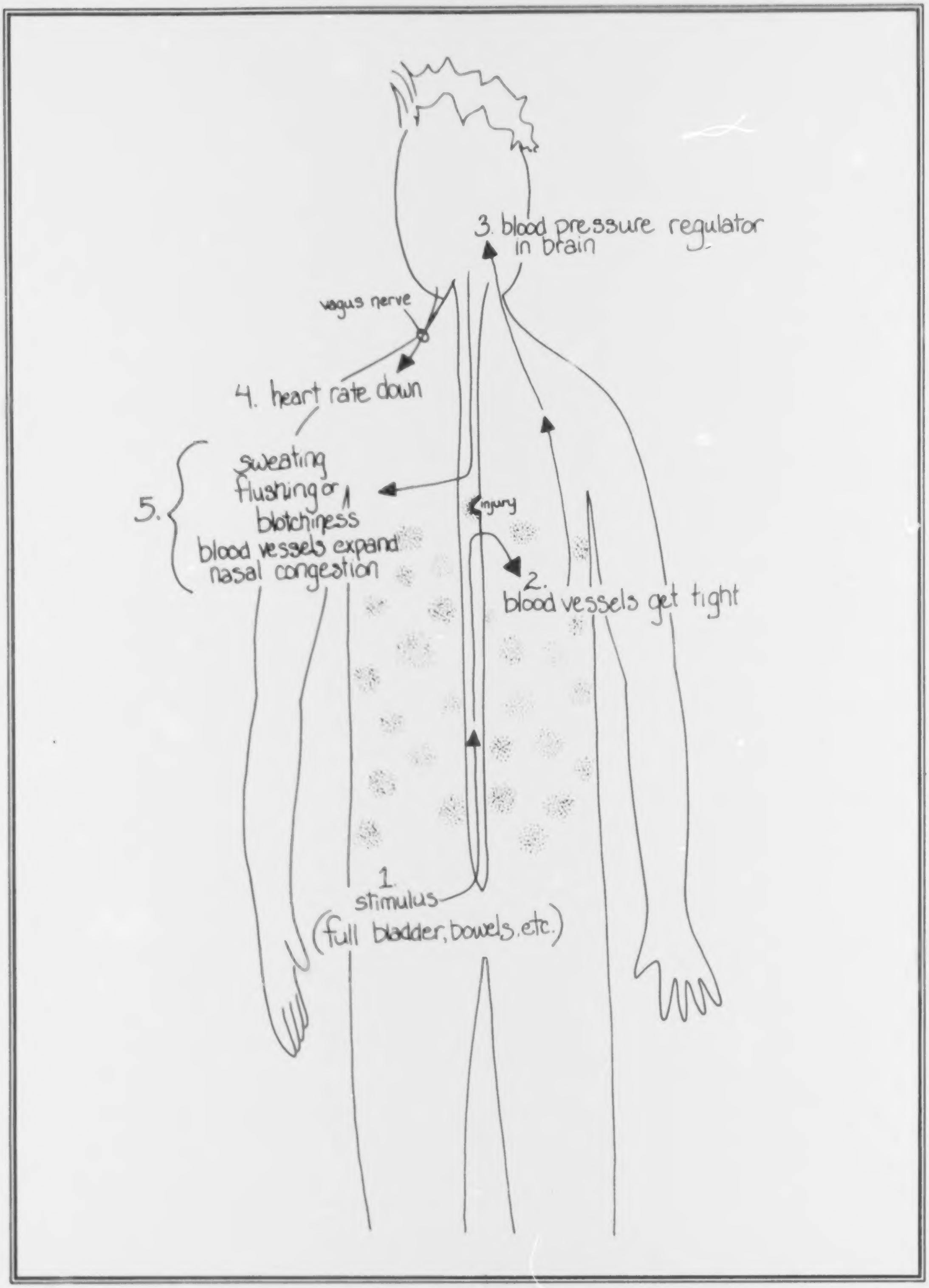

SOLUTION

COMPLICATIONS

A "COMPLICATION" is any medical problem or disease resulting from having had a spinal cord injury. The usual effects of a spinal cord injury on your nervous system, circulation, bowel and bladder are discussed in the chapters on these subjects and are not considered complications.

This chapter discusses how to recognize, prevent and treat some conditions which may become a problem for you. By learning about these complications now, you will understand more of the reasons behind your care. You will be able to avoid many serious problems by using these simple but very important preventive measures.

DYSREFLEXIA


3. blood pressure regulator in brain
vagus nerve
4. heart rate down
5. sweating
flushing or
blotchiness
blood vessels expand
nasal congestion
injury
2. blood vessels get tight
1. stimulus (full bladder, bowels, etc.)

DYSREFLEXIA (AUTONOMIC HYPERREFLEXIA)

Dysreflexia, also called autonomic hyperreflexia, is an abnormal reaction of your nervous and circulatory systems to some irritation below the level of your injury. It occurs in some people whose injury is at or above T-6. It may be mild or severe, frequent or rare, but it is considered a medical emergency because it can cause a stroke and even death if not controlled.

Some people are more prone to dysreflexia than others. A few people have frequent, mild dysreflexia that comes and goes. Others who have never had an episode may suddenly have a severe reaction. If your injury is at T-6 or above, you should be aware of the possibility of dysreflexia and know the signs, causes and treatments so that you can respond promptly and effectively should it occur.

WHAT HAPPENS INSIDE YOUR BODY DURING DYSREFLEXIA

An irritation below the level of injury (most often, a full bladder) sends nerve impulses up the spinal cord which get blocked at the level of injury. This sets off a reflex reaction in the blood vessels below the injury. The blood vessels contract, increasing the blood pressure throughout your body.

The brain attempts to reverse the rise in pressure by sending messages to the heart to slow down, and to the blood vessels to relax. But these messages can only reach the blood vessels ABOVE the level of injury. The heartbeat may slow down, but the blood vessels below the injury remain contracted. The blood pressure may continue to rise to dangerous levels. High blood pressure in the brain can cause a seizure or a stroke if not relieved.

YOU SHOULD MEMORIZE THESE SIGNS OF DYSREFLEXIA:

- POUNDING FRONTAL HEADACHE
- ELEVATED BLOOD PRESSURE, SLOW HEART RATE
- SWEATING AND/OR FLUSHING ABOVE LEVEL OF INJURY
- PALE AND/OR GOOSEBUMPS BELOW LEVEL OF INJURY
- RED BLOTCHES ON BODY
- OTHERS: CHILLS, BLURRY VISION, STUFFY NOSE, FEELINGS OF DOOM

WHAT TO DO:

1. TAKE IMMEDIATE MEASURES TO LOWER THE BLOOD PRESSURE:
   - RAISE YOUR HEAD or sit up straight, lower your legs
   - Remove elastic stockings, binder, tight clothing
2. REMOVE THE CAUSE
   - Empty the bladder. If you usually catheterize at intervals, do so immediately using anesthetic jelly as the lubricant. If you have a permanent catheter, make sure it is flowing freely; if not, irrigate it using one ounce of sterile saline solution or 1/4 strength vinegar and water to dislodge any blockage. If this is impossible, replace it.
   - If emptying the bladder does not relieve symptoms, check the bowel for stool. First insert a tube of anesthetic jelly into the rectum. Avoid digital stimulation which may increase irritation. Wait 10 minutes, then remove stool from rectum.
   - If dysreflexic episode directly followed bowel stimulation, stop the bowel program and insert a tube of anesthetic jelly into rectum.
   - If bladder and bowel treatment do not help, check skin for ingrown toe nail, pressure sores, creases in the sheets or tight clothing - anything which might be irritating your skin below the level of injury. Remove irritant or apply anesthetic ointment or spray to irritated area.

IF CAUSE CANNOT BE FOUND AND REMOVED, GO IMMEDIATELY TO THE NEAREST EMERGENCY ROOM. Take the initiative in informing emergency room personnel about dysreflexia. Not all medical people are familiar with the condition. Take this information with you for the physician's reference.

SUPPLIES FOR DYSREFLEXIA TRAY

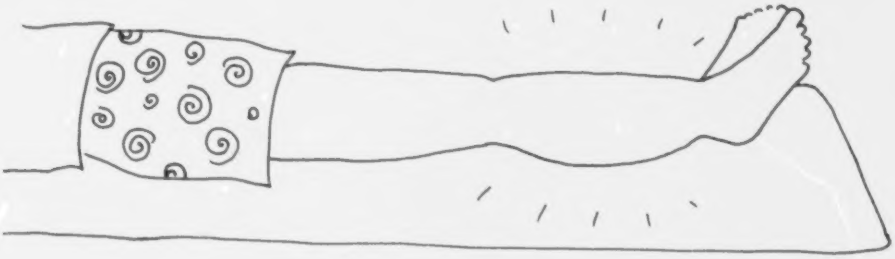
Keep these with you at all times if you are prone to dysreflexia: Anesthetic jelly, ointment, and spray, extra catheters and cath supplies, bowel program supplies, phone number of nearest ER.

THROMBOPHLEBITIS

When you are not moving around, your blood flows more slowly and may pool in the lower part of your body, a condition called VENOUS STASIS. You may be given elastic hose to wear, or a special device called "Jobst pumps" may be used while you are in the hospital to control this condition. A variety of problems may result from venous stasis; one of the more serious is THROMBOPHLEBITIS.

Thrombophlebitis is the formation of a clot (thrombus) and inflammation (phlebitis) on the inside of a vein. This problem is most likely to occur during the few weeks immediately after your injury. However, it is possible for a thrombus to form at any time.

This condition can impair the circulation in your leg and foot and lead to other more serious problems. You need to learn to recognize thrombophlebitis and treat it promptly should it occur.



SIGNS OF THROMBOPHLEBITIS

- RED, SWOLLEN AREA ON ONE LEG
- ONE LEG LARGER (MORE SWOLLEN) THAN THE OTHER
- FEVER, SICK FEELING
- IF THERE IS SENSATION, PAIN

TREATMENT

- GET IN BED AND STAY THERE. DO NOT GET UP UNTIL THE DOCTOR SAYS IT IS SAFE.
- INFORM YOUR DOCTOR OF YOUR SYMPTOMS IMMEDIATELY. THE DOCTOR MAY PRESCRIBE MEDICATIONS OR OTHER SPECIFIC MEASURES TO TAKE.
- AVOID MOVING YOUR LEG AROUND OR PUTTING PRESSURE ON IT. DO NOT MASSAGE OR RUB THE LEG.
- ELEVATE THE FOOT OF THE BED ON BRICKS OR BLOCKS, SO THAT THE WHOLE BED IS SLANTED. DO NOT ELEVATE YOUR LEG ON PILLOWS, THIS MAY IMPAIR THE CIRCULATION.
- WITH YOUR DOCTOR'S APPROVAL, APPLY WARM COMPRESSES TO THE INFLAMED AREA, CHECKING SKIN FREQUENTLY TO AVOID BURNS

PREVENTION

- Aspirin may be prescribed to prevent this condition. Take it faithfully.
- Wear your TED hose (elastic stockings) if ordered and keep them on for the recommended time.
- Do your weight shifts religiously and avoid long periods of sitting without breaks. Put your feet up periodically to allow better blood flow in your legs.
- Avoid bumping or injuring your legs during transfers. Even though you cannot feel it, an injury can result in a clot.

PULMONARY EMBOLISM

In addition to impairing circulation in the leg, thrombophlebitis can lead to PULMONARY EMBOLISM. This is a rare but life-threatening complication in which a blood clot breaks loose and gets into the blood stream. The clot travels to the lungs and blocks the flow of blood into the lungs. You should be aware of this possibility because prompt treatment may save your life. If you notice the signs below, even if you are unaware of having thrombophlebitis or any other problem, call an ambulance or go immediately to the nearest emergency room for treatment.

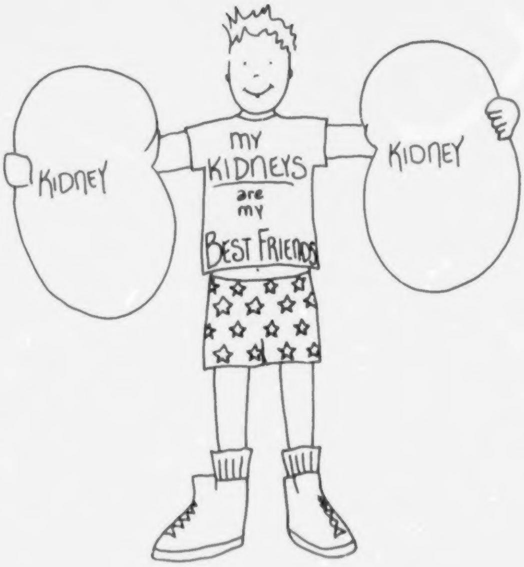
SIGNS OF PULMONARY EMBOLISM:

- CHEST PAIN
- SHORTNESS OF BREATH
- RAPID PULSE
- FEELING OF ANXIETY OR DOOM

KIDNEY PROBLEMS

The kidneys are very delicate and complicated organs which do several important jobs. Most important, they filter poisonous waste products and excess water from the blood and remove them from the body as urine. They also produce substances needed for blood building, and control the amount of some minerals and vitamins in the body.

In the past, kidney disease has been one of the leading causes of death among spinal cord injured people. This is no longer true because intermittent catheterization and other measures are now used to protect the kidneys from damage. But immobility, catheterizations, low blood pressure and kidney stones can all be hard on your kidneys. You need to check routinely for early signs of problems. At least once a year, you will need a complete examination and evaluation of your kidneys, ureters and bladder by a doctor who specializes in this area of the body (UROLOGIST).


KIDNEY
MY KIDNEYS are my BEST FRIENDS
KIDNEY

Following is a description of some common kidney problems, their signs and symptoms, and the measures you can take to prevent them. If you suspect you have a kidney or bladder disorder, contact your urologist immediately.

RENAL CALCULI (Kidney Stones)

After SCI, "stones" may form in your kidneys if too many minerals become concentrated in the urine. The stones can cause pain, spasms, or dysreflexia as they are passed; or, they can block the flow of urine, causing pressure and damage to the delicate filtering system of the kidneys.

Drinking plenty of fluids will help reduce the chance of kidney stones forming. Ask your doctor whether you should limit your intake of dairy products and other foods high in calcium.

KIDNEY AND BLADDER INFECTIONS

When you put a catheter in the bladder, or when urine stays too long in the bladder, the risk of infection increases. Kidney infection sometimes results from a neglected bladder infection which spreads up the ureters due to REFLUX (urine backing up into the kidneys.) Without treatment, kidney infection can cause permanent damage and decreased kidney function.

To prevent infection, you should always use careful clean technique when you catheterize and keep your equipment very clean. Drink plenty of fluids and take any medications which are ordered to reduce bacteria (germs) in the bladder.

Infections in the bladder or kidneys are treated with antibiotics. Be sure to report any symptoms to your doctor and follow treatment orders fully. In particular, it is important to take all the medication ordered, not to stop taking it when your symptoms disappear.

KIDNEY FAILURE

After SCI, your blood pressure may be quite low because your blood vessels are dilated (relaxed) below the level of your injury. If you have a high injury and you become severely dehydrated due to diarrhea, vomiting, or other causes, it is possible your blood pressure could fall dangerously low. The kidneys may actually "shut down" or collapse and stop working altogether. Waste products then build up in the body and can cause severe illness.

Ordinarily, if you drink plenty of fluids and do not suffer from postural hypotension, your blood pressure will be adequate for kidney filtration. Prevent dehydration by drinking adequate fluids and avoiding too much alcohol or other substances which draw fluid out of your body. (For instance, diuretic medicine or teas should not be used without a doctor's recommendation.) Get medical help if you get too sick to drink fluids.

COMMON SIGNS OF KIDNEY DISORDERS

Normally, an early sign is PAIN in the middle or lower back.

Other signs of kidney or bladder problems include:

- Reduced amount or very concentrated (dark) urine
- Blood, grit or cloudiness in the urine
- Unexplained increase in spasms or dysreflexia
- Nausea, vomiting, or diarrhea
- Fever, sick feeling
- Increased swelling in feet, legs, hands or face

TO PREVENT KIDNEY DAMAGE:

- REPORT ANY OF THE ABOVE SIGNS TO YOUR UROLOGIST RIGHT AWAY
- AVOID DEHYDRATION (getting too dried out) by always drinking as much fluid as you are allowed, usually about 1 1/2 to 2 quarts a day, spaced throughout the waking hours. (Vomiting, diarrhea, and drinking alcohol can cause dehydration.)
- Ask your doctor about whether to limit your intake of dairy products and other high calcium foods. You may need less calcium than before your injury to avoid kidney stones.
- REDUCE YOUR SALT intake as much as possible. This will make less work for your kidneys.
- Use your ELASTIC STOCKINGS OR BINDER if needed to help keep your blood pressure high enough. The filtering system of the kidney cannot work properly when the pressure is too low.

PRESSURE SORES

A pressure sore is a damaged area of skin which results from sitting or lying too long in one position. How long is "too long" depends on many factors. A sore can develop in a matter of hours in some cases. This is why it is so important for you to shift your weight frequently and inspect your skin daily for problems. A pressure sore is much easier to prevent than to cure.

HOW A PRESSURE SORE DEVELOPS

Sores can start on the surface, from an abrasion caused by rubbing or any other break in the skin. Or they may start under the surface, if pressure keeps fresh blood from getting to the skin. Before long the skin starts dying from lack of oxygen and build-up of waste products.

The sore usually first appears as a reddened, bruised, warm or hard area. If you press on the area and it becomes white and then turns red again, we say that it "blanches" which means there is still a good blood supply to the area. If the area is soft and does not blanch, this means the small blood vessels in the area are breaking down and fluid is leaking out. The affected skin is starting to die.

If you continue to put pressure on a sore like this, a blister will soon form under the surface, as fluid builds up between the surface layer of skin and the damaged layer below. When this breaks open there is an open wound involving one or more layers of skin and underlying tissue. Infection may easily develop if this wound is not treated.

Continued pressure causes deeper and deeper layers of skin and flesh to break down, until the wound reaches to the bone. At this point, OSTEOMYELITIS (infection in the bone) is a danger, and permanent bone damage can result. Even more dangerous, an infection can get into your blood stream and affect your whole body. This can kill you if it is not treated.

Because the sore may start under the surface, it is often not noticed at first, or it may seem minor. Often a huge sore may have a very small opening, or none at all. Do not ignore a discolored or mushy area. By the time it reaches the surface, a sore may not heal by itself even if you stay off it for weeks.

PREVENTION

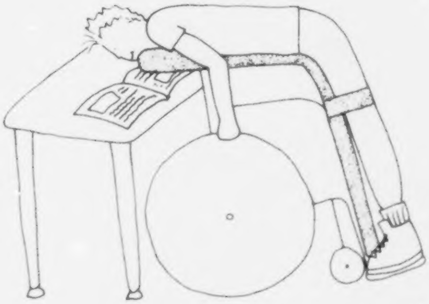
The way to prevent sores is to DO WEIGHT SHIFTS AT FREQUENT INTERVALS to allow good circulation to your pressure points. This means turning every two to four hours when you are lying in bed, and relieving pressure points for a few minutes every hour or more often when you are sitting in your chair.

There are also several devices you can use to help relieve pressure and protect your skin. *Please read Chapter 3 on Skin Care and the section on wheelchair cushions in Chapter 17 for a thorough explanation of proper prevention techniques.*

TREATMENT

AT THE FIRST SIGN OF A PRESSURE SORE:

GET OFF THE REDDENED AREA!!!!! Go to bed or get in a position where there is NO pressure on the red area. If you have red areas on both hips, lie on your stomach (prone) as much as possible. Keep the pressure off completely until all signs of redness are gone.



On a manual wheelchair, a platform can be fashioned which will allow you to ride prone if you do not want to stay in bed. (See the illustration.) Keep up your weight shift schedule in your chair and your turning schedule while in bed.

IF THERE IS AN OPENING IN THE SKIN:

In addition to the above, take measures to prevent infection. Wash the area with soap and water and dry it gently with a sterile gauze bandage. Apply a sterile gauze dressing and change it frequently. Keep the area very clean and observe for signs of infection, including swelling, increased redness, foul odor, or pus. If you get a fever or feel sick, call your doctor or public health nurse.

IF A WOUND IS DEEP OR INFECTED OR DOES NOT HEAL:

See a doctor. Do not wait until you have huge open sores. A great deal of damage can occur before a sore looks bad at all. Deep sores often require surgery to heal properly, since the tissue may be too damaged to grow back naturally. You may anticipate several weeks or even months confined to bed, and deep, disfiguring scars. Without treatment, such a sore can lead to life-threatening infections.

HETEROTOPIC OSSIFICATION

Heterotopic Ossification (H.O.) means "misplaced" deposits of bony tissue. This is an unusual but possible complication of SCI.

After an injury to the central nervous system (brain or spinal cord) some people get abnormal deposits of bone around their joints. These deposits can cause swelling, redness and stiffness of the joints, and pain if there is sensation. Eventually the joints may solidify to the point where they cannot move.

Doctors have no idea why this happens. Once this process has begun, there is little that can be done medically to prevent or stop it.

SIGNS

One or more of these signs may be present:

- Swollen areas around the joints, usually the hips and knees, and less frequently the shoulders
- The area may be red but often is not
- Pain, if in areas with feeling

DIAGNOSIS

If signs of H.O. occur, a blood test will be done to check for chemical changes in your body. X-rays also will reveal the abnormal bone tissue.

TREATMENT

Range-of-motion exercises and warm compresses may be used to reduce stiffness and pain.

In some cases, surgery may be needed to release hardened joints.

SCOLIOSIS

Scoliosis is an abnormal curve in the spine. This can be a problem after SCI if you are still growing. The muscles below the level of injury do not provide support for your spine and your spine does not grow evenly. Scoliosis, if it is severe, may cause your body to look crooked or lop-sided. It can also put abnormal pressure on your internal organs, causing shortness of breath or other medical problems.

SIGNS

The spine will not appear straight.

There may be more skin folds on one side of the body than the other.

With extreme scoliosis, there may be shortness of breath, frequent lung infections, heart or stomach problems.

TREATMENT

If you develop scoliosis, you may be given a brace to support your body and help keep your spine lined up straight while you are growing. The brace can help slow down the curving of the spine, though it may not prevent it altogether.

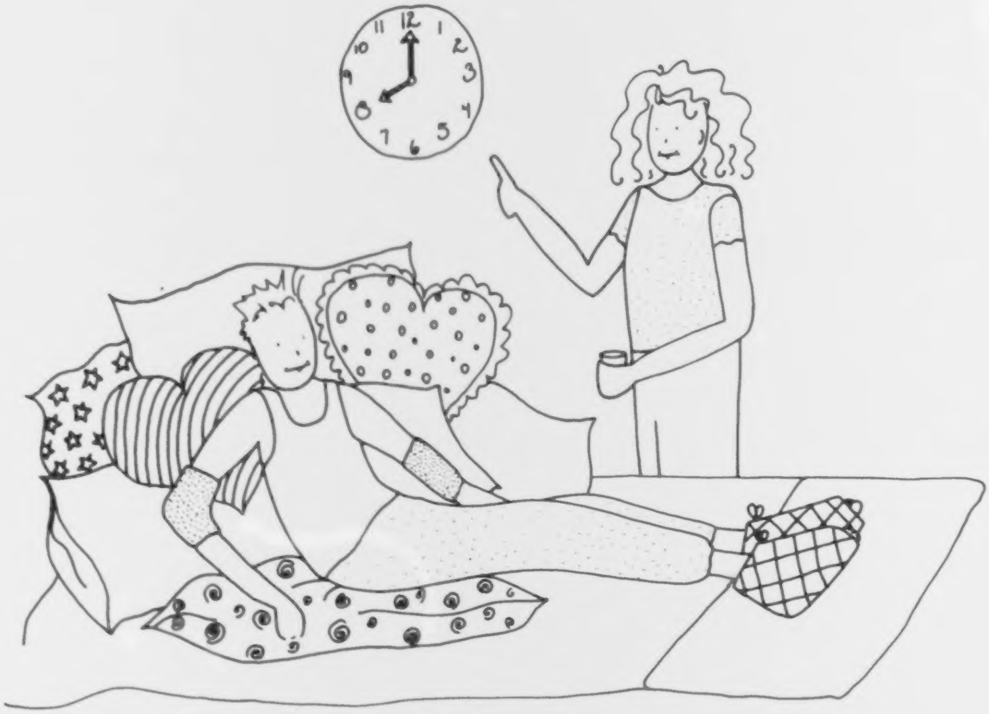
In severe cases, surgery may be needed to correct this problem. A "SPINAL FUSION" is a surgery which lines up the spine and holds it in place with metal rods. Your spine will not be quite so flexible after this surgery but it will stay straight.

CHAPTER TEN

MEDICATIONS

IN THIS CHAPTER YOU WILL LEARN:

- What you should know about your medications.
- What you should do if you question a medication order.
- Who is responsible for making sure you take and know about your medications.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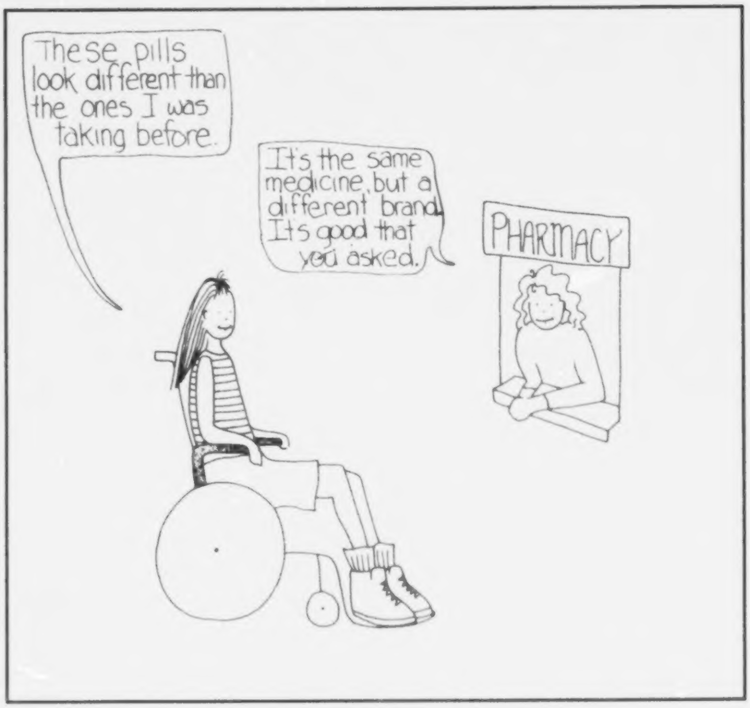
MEDICATIONS

After SCI, you may be given medications to prevent complications or to treat infections or other abnormal conditions.

Medications can help you stay healthy and comfortable, but they also can cause discomfort and damage if they are misused. You should always check with your doctor, who understands the chemical needs of your body, in making any decision about your medication. You have the right to question whether a medication is needed or not, and to get another doctor's opinion if you are not sure. But for your own safety, never start or stop taking any drug without a doctor's advice.

In the hospital, the nurses will give you your medication. But while you are here, you need to learn what medications you are taking and become an expert on them, so that when you go home you will know when and how much to take. This is a responsibility you should take seriously because this can make the difference between health and serious illness for you.

Before you leave Shriners Hospital, you may be given prescriptions for the medications you need to take when you go home. You need to have these prescriptions filled at a pharmacy, and to get them renewed if necessary. You should always consider YOURSELF responsible for taking your medication and for watching out for any side effects, even if someone else helps you take them. This is because it is YOUR body and YOUR health at stake. Be sure to let your doctor at home know what medications you are taking, and report any problems or side effects right away.


These pills look different than the ones I was taking before.
It's the same medicine, but a different brand. It's good that you asked.
PHARMACY

RULES FOR SAFE DRUG USE:

- NEVER START OR STOP TAKING ANY DRUG OR MEDICATION WITHOUT A DOCTOR'S RECOMMENDATION. THIS INCLUDES NON-PRESCRIPTION DRUGS.

- TAKE YOUR MEDICATIONS AT THE RIGHT TIMES AND THE PROPER DOSAGE.

- KNOW THE SIDE-EFFECTS (POSSIBLE HARMFUL EFFECTS) OF TAKING THE MEDICATION, SUCH AS DROWSINESS, NAUSEA, SENSITIVITY TO SUNLIGHT, OR BLOOD PRESSURE CHANGES.

- DOES THIS MEDICATION MIX SAFELY WITH OTHER DRUGS OR ALCOHOL?

- IF YOU DISAGREE WITH YOUR DOCTOR OR WITH A PHARMACIST REGARDING YOUR MEDICATION, DISCUSS IT WITH THEM. YOU SHOULD GET A SECOND OPINION IF, AFTER DISCUSSING IT, YOU FEEL THAT A MEDICATION ORDER IS NOT RIGHT FOR YOU.

MEDICATION CHECKLIST

Why should you never start or stop taking any drug or medication without a doctor's recommendation?

For each medication you are taking, explain the following:

1. WHY are you taking it? (What does it do?)
2. What is the EXACT DOSE you are taking?
3. At what TIME(S) is it taken?
4. What should you do if you miss a dose?
5. What are the SIDE EFFECTS (possible harmful effects)?
6. Is it safe to mix this drug with other medication? With alcohol? With milk or other foods?
7. When should you stop taking this medication?

CHAPTER ELEVEN

PHYSICAL THERAPY

IN THIS CHAPTER YOU WILL LEARN:

- The purposes of Physical Therapy.
- Why range of motion exercises are important.
- How to preserve and increase your mobility.
- Three different types of transfers.
- About wheelchair skills and ambulation.

WELCOME TO REHABILITATION

The overall goal of rehabilitation is to help you become as independent as possible. In Physical Therapy we will help you:

- Increase your strength, flexibility, and coordination.
- Learn to use your wheelchair and any other equipment such as braces or walkers.
- Learn to transfer safely or teach others to help you.

As you know, your ability to move has been impaired because of your spinal cord injury. Just how much you will be able to move depends mostly on the nature of your injury: the level, the degree of completeness or incompleteness, and whether your injury was upper motor neuron or lower motor neuron. Physical Therapy cannot restore lost movement, but it will help you make the most of what you have. It will also help you keep your body flexible so that if and when movement does return, you will be able to take advantage of it.

It is hard when you first start therapy to know what goals to set, because often it is not known exactly what your abilities and limitations will be. Our general approach is to set goals based on your CURRENT level of ability, always keeping open to new developments. This keeps our work with you realistic as well as optimistic. As you progress in therapy, we may set new goals to keep you challenged but not overwhelmed.

Your attitude is an important factor in how useful and effective your therapy will be. Try to keep a positive attitude and celebrate the little steps along the way. As in other areas of life, you will get satisfaction in knowing you have tried your hardest and done your best. Keep your aim set on INDEPENDENCE. Remember, this is not a competition, it's an opportunity to grow.

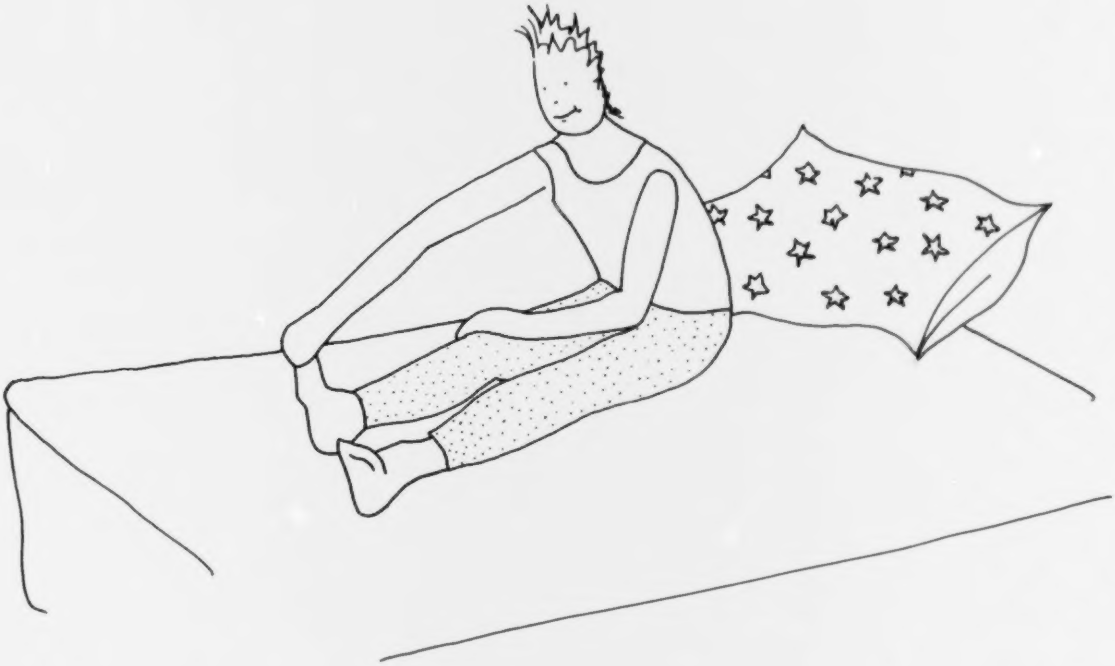
Keep in mind, too, that you and your therapist are human beings. You both have good days and less-than-good days. Sometimes you may feel discouraged, or it may seem like no one appreciates all the work you are doing! But we do. Talk about any problems you have, let us know what you need. With your full participation, we can work together to overcome the obstacles and achieve your goals.

RANGE OF MOTION

Range of motion refers to the movement of joints and the flexibility of the connective tissues surrounding the joints. Normally each joint has a certain range through which it can be moved. If a joint is not moved every day, the range tends to get shorter. Eventually, a CONTRACTURE may form: the tendons and ligaments surrounding the joint become tight and stiff, and bony deposits may form within the joint itself. This can be very hard to correct once it occurs.

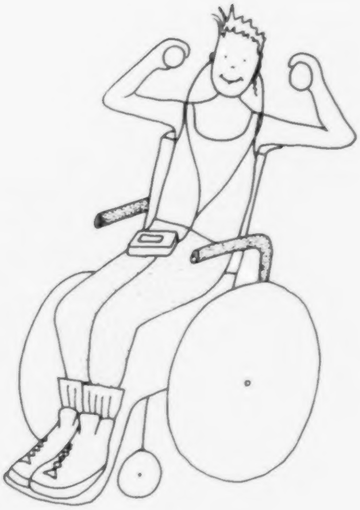
The best way to avoid contractures is to take every joint through its complete range regularly. This keeps the tissues stretched out and flexible. Range of motion exercises also help reduce spasms for many people.

You will be taught how to position your limbs to help keep your joints flexible. In particular, you will be encouraged to lie prone (on your stomach) to stretch out the joints in your hips and knees which are flexed all day while you are sitting. Other measures which may be used are the tilt table or standing frame. These devices provide valuable weight-bearing activity for your bones and they are good for your joints.

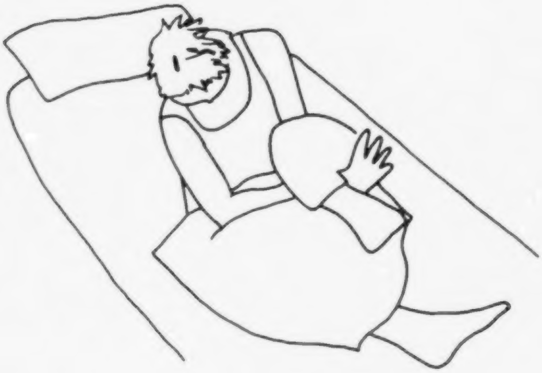


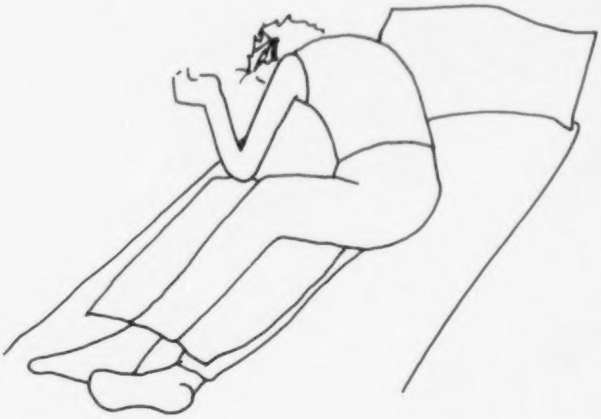
STRENGTH AND MOBILITY ACTIVITIES

One important area you will be working on in Physical Therapy is developing your useful muscles to make up for the areas where movement is missing. Depending on the level of your injury, this may include neck, shoulder, back, arm or hand muscles. You will be put on a weight lifting program which may include use of a pulley system, cuff weights and/or dumb bells. Your endurance will be developed by gradually increasing the time you propel your wheelchair and perform other tasks.

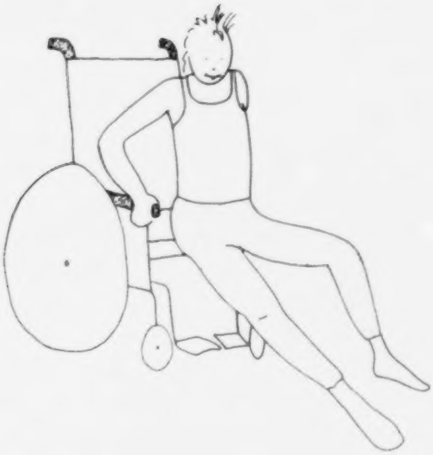


Along with strengthening exercises you will be working on mobility skills. You may need to learn special ways to turn, sit up, lie down and balance yourself. We will work on new movement patterns and balance techniques to help you be as mobile and independent as possible.





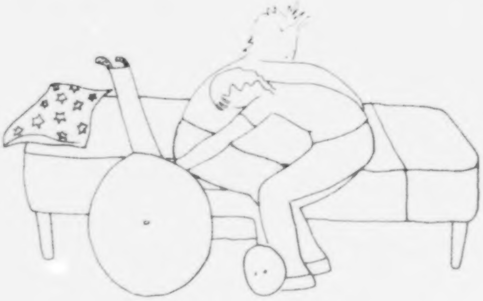
TRANSFERS



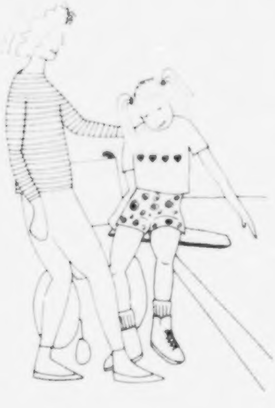
Independent Transfer

There are many ways to transfer. The three basic types of transfers are *independent, assisted,* and *dependent.* How you transfer from one place to another will depend on many factors, including your size, strength, motivation and level of injury. You will learn to transfer yourself or to instruct an assistant to help you transfer from bed-to-wheelchair, wheeichair-to-car, wheelchair-to-tub or shower, and back again. You may also work on chair-to-floor and floor-to-chair transfers.

As you develop your strength and mobility, you will practice various methods and surfaces until you feel comfortable with the transfers that suit your needs. If you need assistance, you will be trained to describe each step so that you can instruct a helper quickly and effectively when necessary.



Dependent Transfer



Assisted Transfer

Sometimes equipment may be needed for a safe transfer. Some people who find it hard to transfer by themselves can do so with the help of a transfer board, which provides a smooth, even surface to bridge the gap between bed and chair. A Hoyer lift is a hydrolic pump lift with a seat which can be used for large or very tall people or those with high injuries. Equipment will be provided when it is necessary, but we encourage you to use as little equipment as possible. This keeps your life simpler and reduces your costs, but even more important, keeps you as strong and independent as you can be.

WHEELCHAIR SKILLS

There are many kinds of wheelchairs and many optional features available. When you come to Shriners Hospital you will use one of the hospital wheelchairs until we can decide exactly the best type of wheelchair for you. An appropriate wheelchair will be provided if you need one.

In choosing the right chair for you, several factors are considered: your level of injury, your size and strength, your tolerance for sitting upright, the accessibility of your home, and the vehicle you will be traveling in. You will get to choose the color and some other style features.

If you have a low injury with good balance and arm strength, you will use a manual wheelchair in a standard or sports style, depending on your lifestyle and interests. With a high injury you may be able to use a manual chair if you have some use of your arms. Wheel pegs may be added to help you manipulate the chair.

If you have limited use of your arms, you may need an electric wheelchair to achieve your maximum independence. These are equipped with hand, chin or breath controls, and may also have such features as an automatic recliner for independent weight shifts.

While electric wheelchairs have many advantages, they also have limitations. They are very heavy, making it impossible to take them up and down stairs. A ramp or elevator may be needed at home. They require a van for transport, as they do not fold up to fit in a car. They need to be recharged every night in order to function, making it necessary to stay near a source of electricity at all times. For these reasons, if you do require an electric wheelchair you may also be given a manual chair to use in situations where the use of the electric chair is difficult.

If you use a manual chair, the wheelchair skills you will learn in Physical Therapy will include manipulating the brakes, armrests, foot plates and other movable parts; pushing on flat surfaces and then on increasing levels of graded surfaces; turns and stops. You will also learn to mount and descend curbs, to balance on your rear wheels ("wheelies"), to do weight shifts, and to transfer yourself from the chair to bed, a car, or the floor, and back again.

If you use an electric wheelchair, you will learn how to use the hand, chin or breath controls, how to maneuver curbs and other obstacles, how to weight shift, and how to transfer in and out of the chair. If you require assistance in any aspect of wheelchair use or transfers, you will also be trained to instruct your assistants in how to perform these tasks safely.

AMBULATION

The first question on everyone's mind after a spinal cord injury is, "Will I be able to walk again?" This is a very difficult question to answer, especially if you have an incomplete injury. Right after an injury, it is difficult to predict exactly how much function will return to your limbs. People may have varying degrees of return for two or more years after an incomplete spinal cord injury. *(Please see Chapter 2 on the Nervous System for an explanation of spinal shock and complete and incomplete injuries.)*

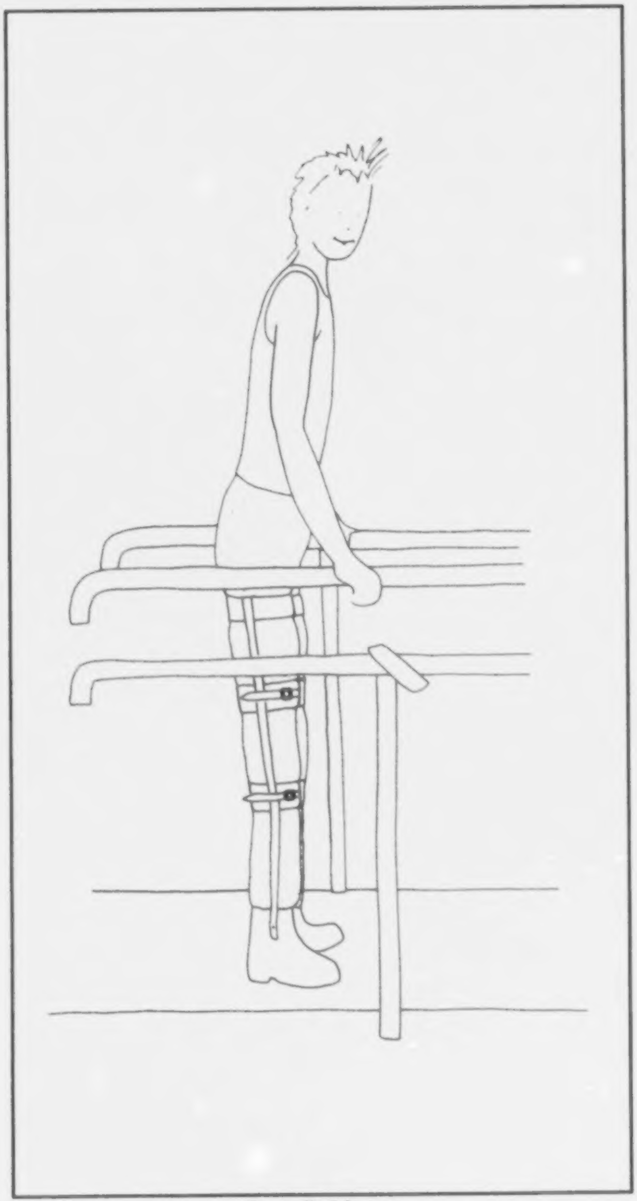
Many people with complete cervical injuries (above C-8) stand either on a tilt table or in a standing frame as part of their therapy, but are not able to walk. With an injury in the high thoracic region (above T-7 or 8) you may be able to walk with long-leg braces and a walker. With a lower thoracic injury (T-8 to T-12) you may be able to walk with crutches and long-leg braces. An injury in the lumbar area may allow you to walk with crutches and short leg braces. However, all this depends on your size, strength, motivation, and the completeness of your injury.

It is important to understand that even if ambulation is possible, it will probably be limited. Time and energy limitations may require that you use your wheelchair most of the time.

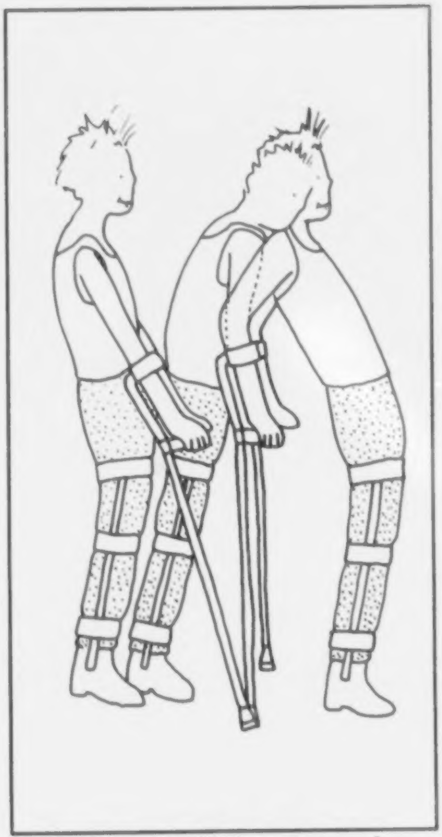
Nevertheless, even limited walking can increase your mobility at home, at school or at work and will be good for your bones, your circulation, your skin, and your state of mind. Even standing on a tilt table can help reduce contractures, spasms, and bone loss, and improve circulation and kidney function. This is why we encourage standing and walking activities from the beginning.

GAIT TRAINING

Gait training usually begins at the parallel bars. If possible, you will then progress to the use of a walker or forearm crutches. There are several different ways of walking; you will be trained according to your abilities and motor control. Your training may include stairs or inclines as well as flat surfaces. Learning how to fall and to regain a standing posture are important too, since sooner or later you are bound to have an opportunity to use these skills!

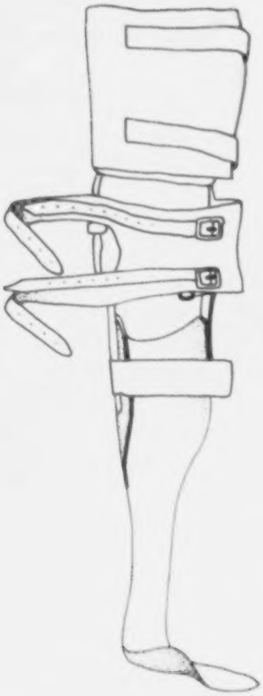


Parallel bars



Walking with braces and crutches

BRACES

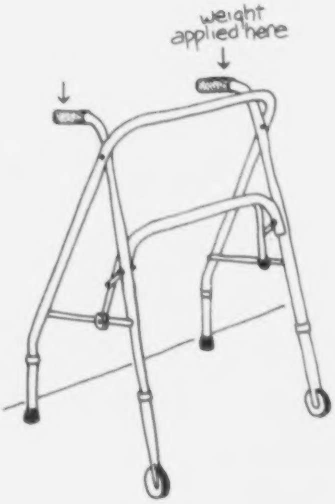


Braces are sometimes used to support your legs when you walk. The braces may include joints for the hips, knees, and/or ankles. They may be made of metal and leather, with shoes attached, or they may be plastic and fit inside your shoes. Some braces include straps that go around your hips to help you balance or stabilize your gait.

EQUIPMENT

By the time you have completed the Rehabilitation Program at Shriners Hospital, you may have accumulated various types of equipment or devices to help you be more functional and independent. These may include: your wheelchair, sliding board, braces, walker or crutches, or other devices.

It is important that you learn to maintain your equipment in good condition. Keep and study any manuals or instructions included with your equipment. Establish a relationship with the company that provided your equipment BEFORE you need parts, repairs or modifications. They are an important link in your support system. *(See Chapter 17 on Equipment for more about taking care of your wheelchair and other equipment.)*



CHAPTER TWELVE

OCCUPATIONAL THERAPY

IN THIS CHAPTER YOU WILL LEARN:

- The purposes of Occupational Therapy.
- About some equipment that may be useful to you.
- Some safety tips and helpful hints for eating, hygiene, dressing, grooming, transfers, and other self-care activities.

INTRODUCTION TO OCCUPATIONAL THERAPY

The goal of occupational therapy is to help you become as independent as possible. The occupational therapist will evaluate your performance in activities of daily living (ADLs), strength, range of motion of your joints, sensation and coordination. The therapist will discuss this evaluation with you, and develop a treatment plan with you. Programs may include the following areas:

ACTIVITIES OF DAILY LIVING TRAINING

The therapist provides training and equipment as needed to permit you to become more independent. This may include such things as getting from your wheelchair to a bed, toilet, car and other places. It may also include eating, hygiene, dressing, bathing, cooking, homemaking, communication skills, community reorientation, predriving assessment and prevocational assessment. A home evaluation for wheelchair accessibility and discharge planning will be done as needed.

STRENGTHENING, COORDINATION, AND RANGE OF MOTION

This may include activities or exercises to increase the strength in your arms. You may also be taught how to use substitute muscles for paralyzed muscles. You may be taught to hold and manipulate objects used for daily living skills. The therapist will maintain or improve range of motion in your arms, and teach you how to do self range of motion on your arms, if needed. As ordered by the physician, splints may be fabricated to prevent problems, enhance muscle function, or protect the hand.

YOU ARE EXPECTED TO BE READY FOR YOUR THERAPY SESSIONS WHEN THEY ARE SCHEDULED. A THERAPY SCHEDULE FOR EACH WEEK IS LOCATED AT THE NURSES' STATION. WHEN THE TREATMENT IS SCHEDULED IN THE OCCUPATIONAL THERAPY CLINIC, YOU ARE RESPONSIBLE FOR GETTING TO THE CLINIC ON TIME. SOME ACTIVITIES AND EXERCISES MAY ALSO BE ASSIGNED FOR YOU TO DO ON YOUR OWN OR WITH THE NURSES.

ADAPTIVE EQUIPMENT

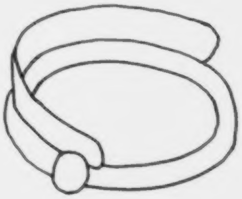
This section describes assistive devices and techniques that may help you be more independent. It may also be used to teach others how to assist you.

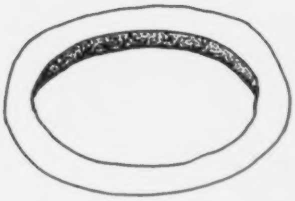
Even though it may be more difficult initially, you will be encouraged to learn to do the tasks with the minimum amount of equipment. There are several reasons for this. It will be less expensive, and you will not have to worry about losing, breaking or forgetting the equipment.

The manual does not include all the information or types of equipment available, nor is it meant to imply you have to do things this way. You are encouraged to talk with therapists, persons with similar disabilities, equipment vendors (listed in the Yellow Pages under "Hospital Equipment and Supplies"), family and friends about other resources. Most importantly, use your knowledge of your own body and your imagination to come up with solutions that are safe and work for you.

ADAPTIVE EQUIPMENT - EATING

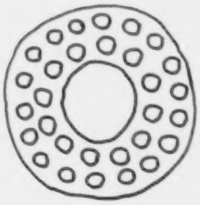
FOOD GUARD snaps onto plate to prevent food from sliding off plate while you are trying to eat. Available in a variety of shapes, sizes and styles.

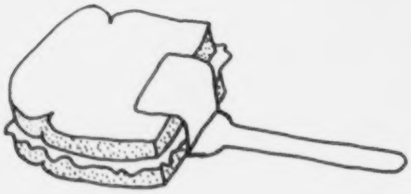




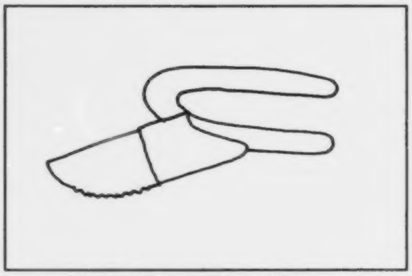
RIMMED PLATE serves the same purpose as food guard, but may be found in department stores. Partitioned rimmed plates are also available in department stores (check in the microwave cookware section.)

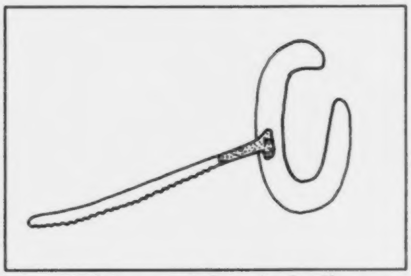
little octopus, dycem non-slip padding or slightly damp face cloth may be used to keep plate from sliding on tabletop

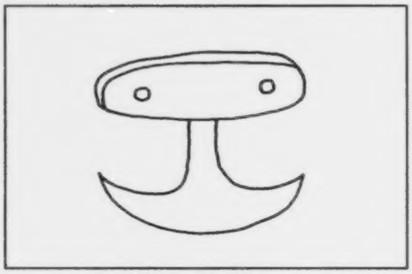


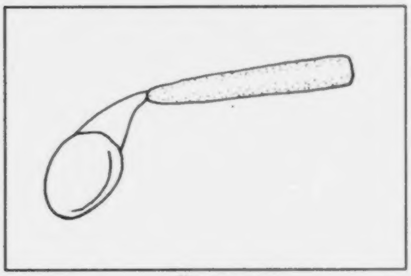


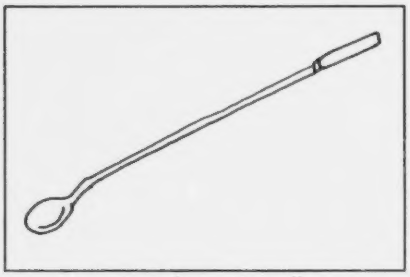
quad-quip sandwich holder slides into utensil holder or splint.

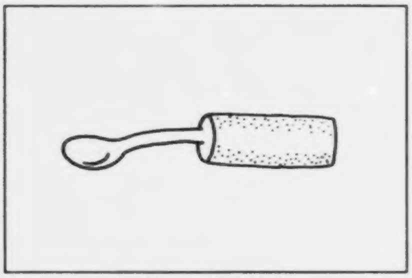

quad-quip knife

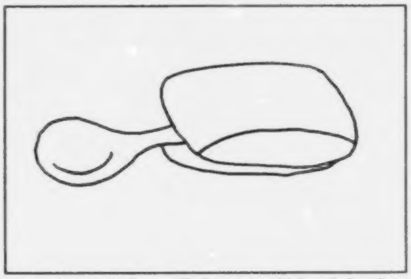

deluxe quad-quip knife

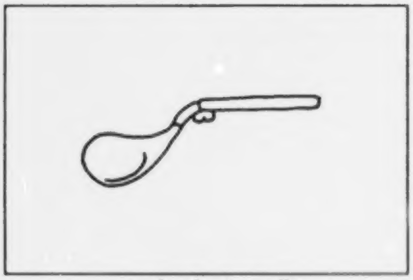

rocking t knife

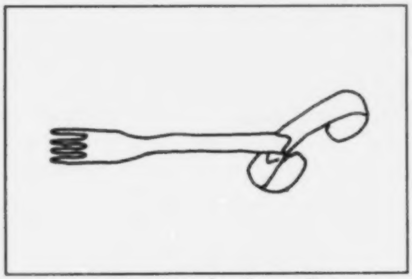

offset spoon


extension utensils

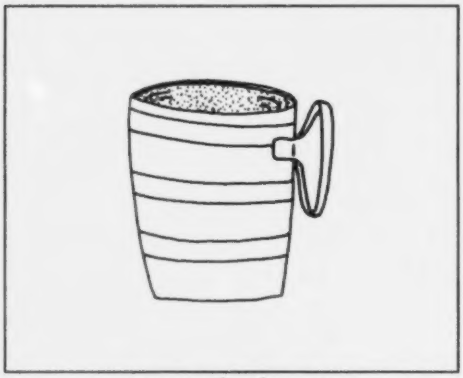

built up handle


universal cuff (utensil holder)

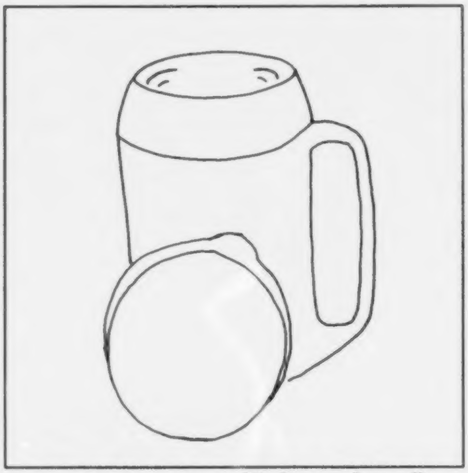

swivel utensil


vertical palm handle

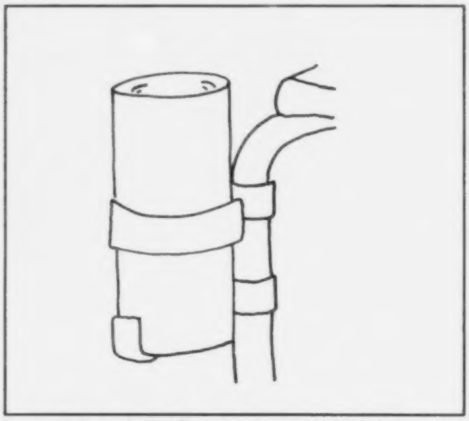
ADAPTIVE EQUIPMENT - DRINKING



personal grip mug



commuter cup with large handle



wheelchair beverage holder

Use insulated cups for warm drinks if you have decreased sensation in your hands.

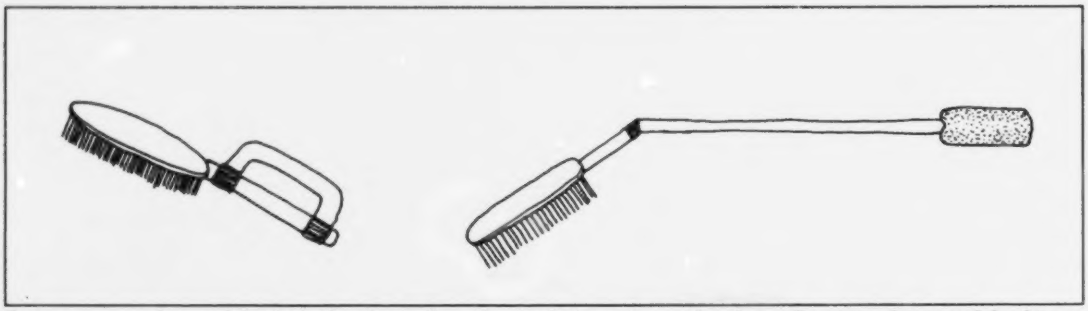
A "commuter" cup may help prevent spills.

NEVER place a cup with hot liquid between your legs.

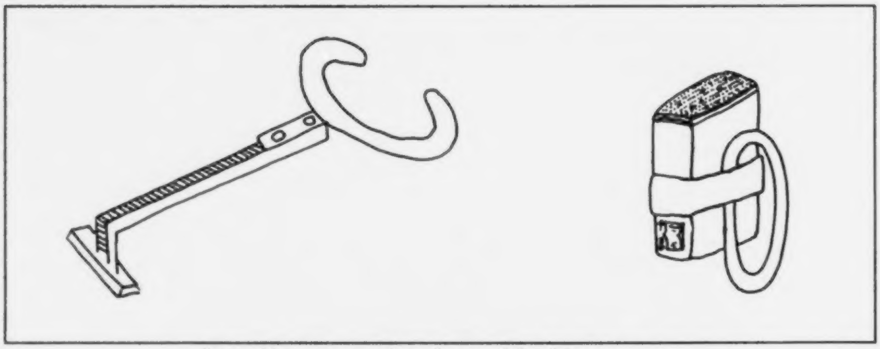
If you have difficulty grasping a cup handle, look for one with a large handle and slide your whole hand into the handle. The personal grip mug allows you to slide your fingers around the handle.

Long plastic straws may be used if you have difficulty picking up a drink. These are sometimes found in grocery stores or novelty shops.

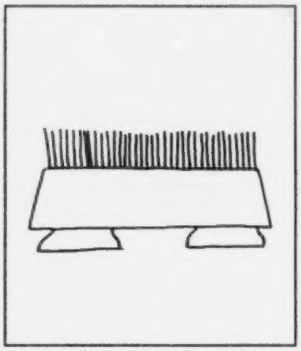
ADAPTIVE EQUIPMENT - HYGIENE



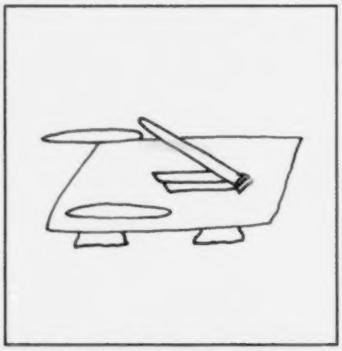
Straps may be added to the handle of a hair brush or the handle may be padded to make it easier to grasp. If you can't reach the top or back of your head a long handled brush or comb may be needed.



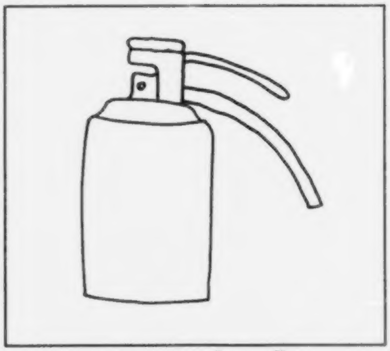
handles may also be added to razors



suction cup brush - used for scrubbing

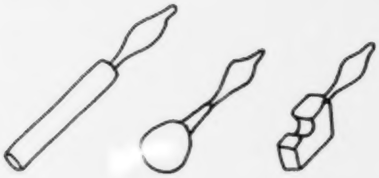


Nail clipper and emery boards may be fastened to a board. Suction cups may be added to the bottom for extra traction.

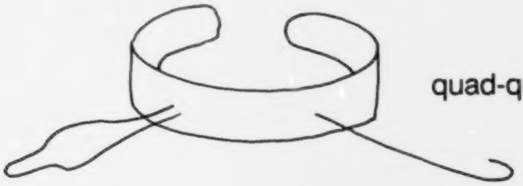


e-z spray handle

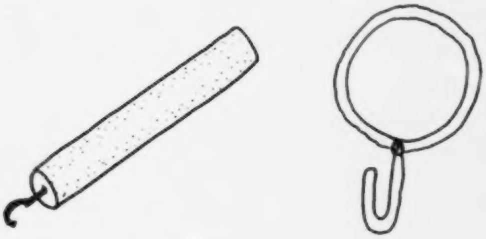
ADAPTIVE EQUIPMENT - DRESSING



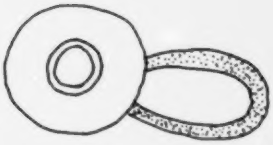
button hook-available in a variety of sizes and shapes. Strap handle can be added if grip is weak.



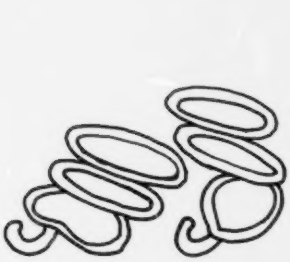
quad-quip button hook and zipper pull



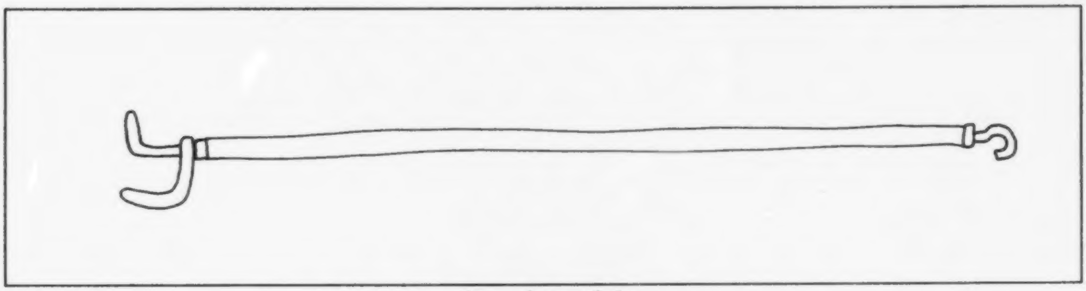
zipper pull-may be made from dowel and small cup hook, or leather loops can be tied to zipper.



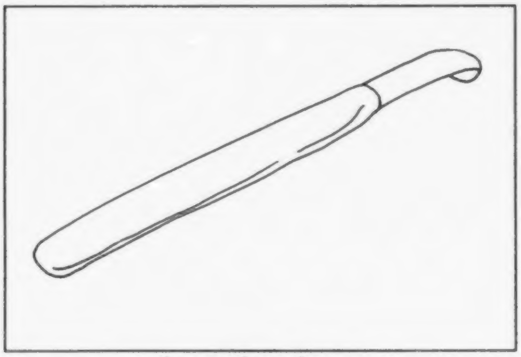
Cuff extender-available in fabric stores. Attaches to button at cuff so you don't have to unbutton cuff when you dress and undress. An alternative is to sew button on with elastic thread so there is more "give" when the hand goes through the sleeve.



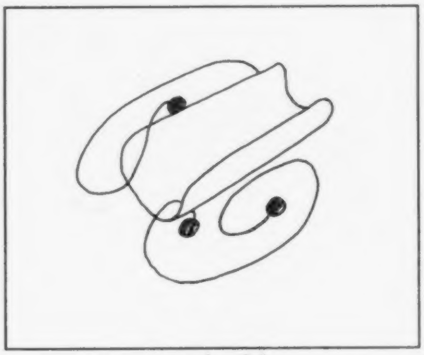
trouser pull-may be made by sewing cotton webbing together in loops. The last loop can have velcro or a hook to attach to the pant loops.



dressing stick



long shoe horn



sock aid

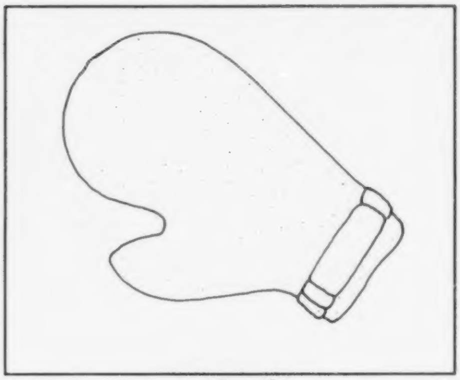
Dressing stick may be made from a dowel, a clothes hook, and a cup hook. This device may be useful if you have trouble reaching your feet to put on and remove clothing.

A long shoe horn may be used to help put on your shoes if you have trouble reaching your feet.

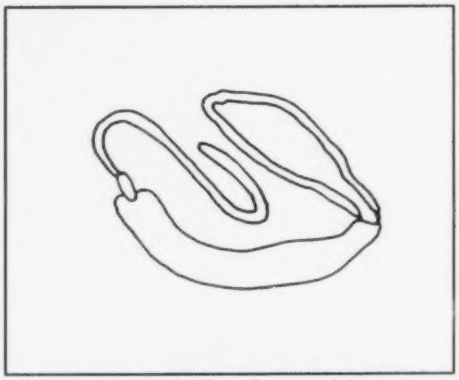
If you have difficulty tying your shoes, consider using slip-on type shoes, buying shoes with velcro closures, or having shoes converted to velcro closures at a shoe repair store.

A sock aid may be useful for pulling on socks if you can't reach your feet.

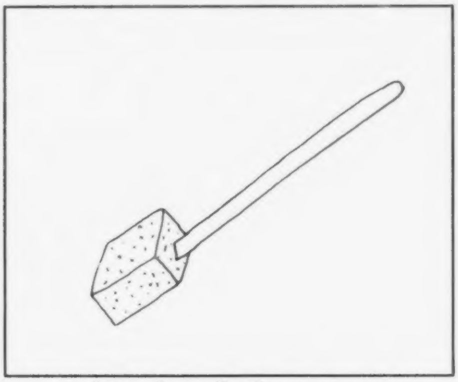
ADAPTIVE EQUIPMENT - BATHING



wash mitt



quad-quip back scrubber

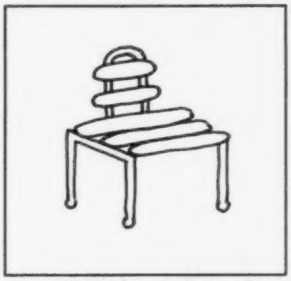


long-handled sponge

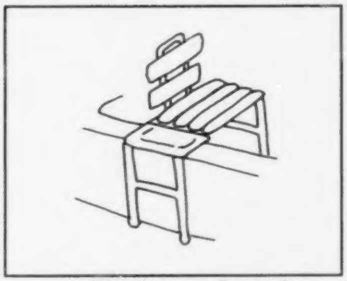
Wash mitt may be made from terrycloth. It has a velcro strap at the wrist to hold it on the hand. A loop or D-ring may be added to the strap so a person with limited hand use can tighten the strap. The thumb shape is optional. A pocket with elastic may be added to hold soap.

The back scrubber may be made from terrycloth and webbing or ribbon for the hand loops.

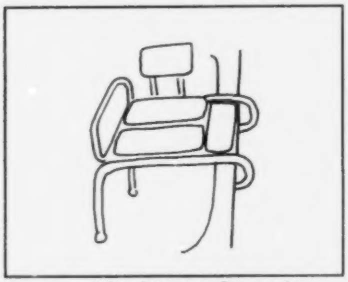
A long-handled sponge may be used for bathing when you can't reach your back or feet. A handle can be added to the brush if grasp is limited.



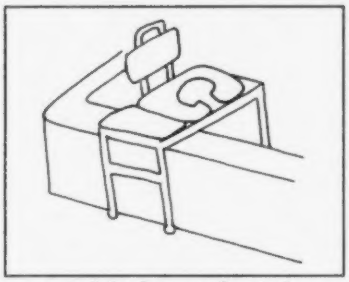
padded tub bench



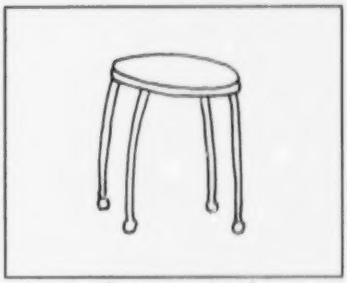
padded transfer tub bench



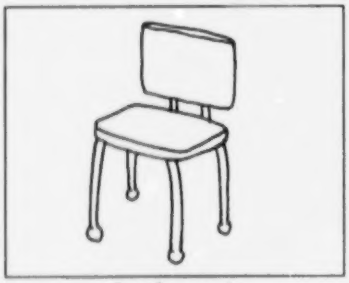
padded transfer tub bench



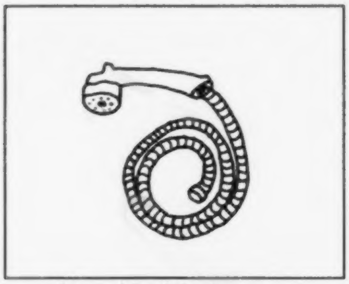
padded transfer tub bench



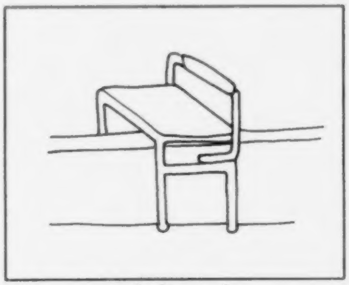
shower stool



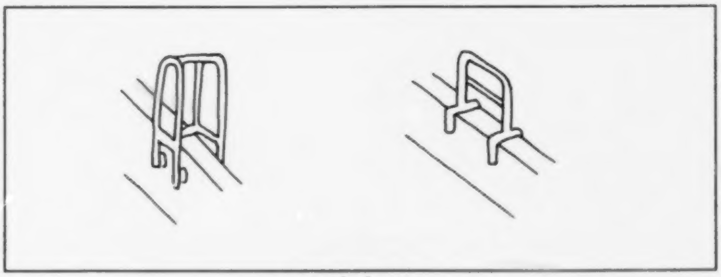
bath seat



hand held shower



tub bench



grab bars

Tub benches and shower seats are available in many shapes and styles. Consult the occupational therapist if you have questions about which type is most suitable for you.

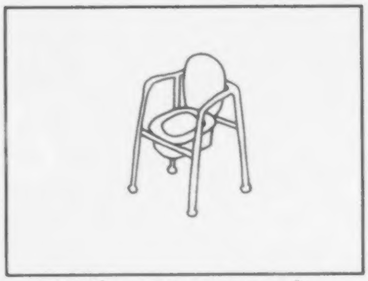
If you have a shower, a combination shower/commode chair may also be an option.

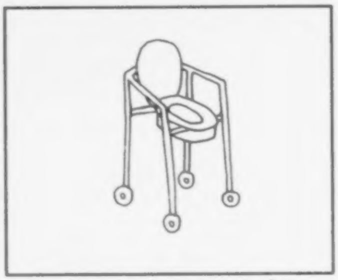
Bath seats may be made from a sturdy captain's chair. Cut off one arm (for easier transfers) and paint the chair with exterior paint.

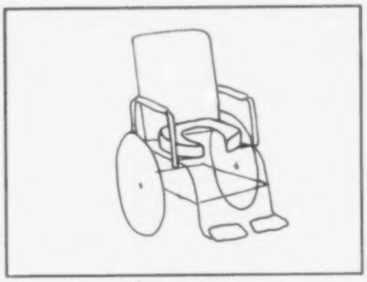
If you have strong arms, you may be able to transfer in/out of the bottom of the tub. Consult your therapist regarding technique.

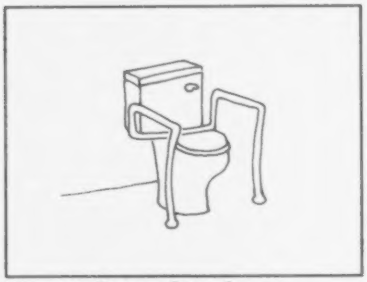
If you have no feeling in your legs, you should sit on a foam or air cushion while in the tub. Always test water temperature with a part of the body where feeling is normal.

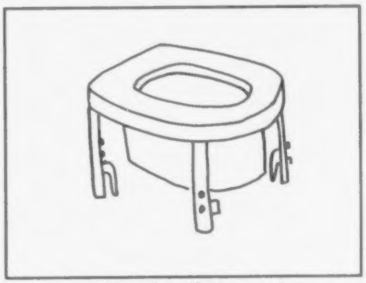
ADAPTIVE EQUIPMENT - TOILETING


stationary commode


wheeled commode


drop arm
shower/commode with
large or small back wheels


toilet safety frame


raised toilet seat

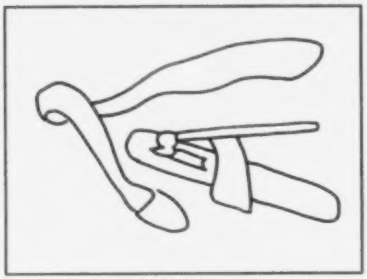
A raised toilet seat, grab bars, commode and/or safety frame may make toileting easier and safer.

Commodes and toilet seats are available with cutouts at the side or back for easier digital stimulation and hygiene.

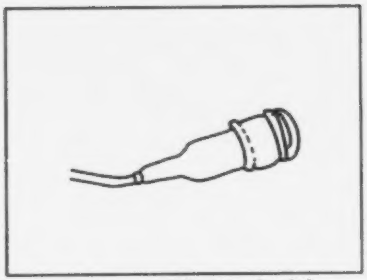
A bedside commode may be needed if mobility is limited or if bathroom is inaccessible.

Padded vinyl toilet seats are available in hardware stores. These are recommended if you have decreased sensation.

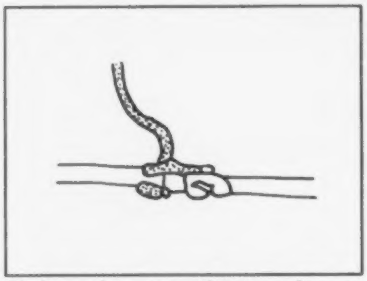
The less equipment you need, the more independent you will be in the community and when traveling.



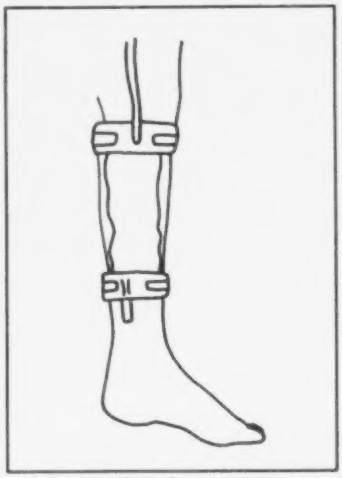
lever catheter clamp



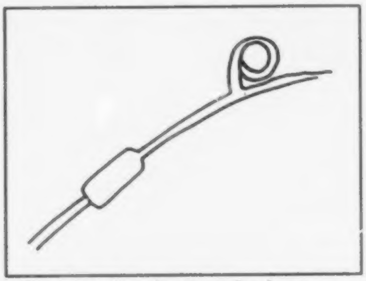
condom catheter holder



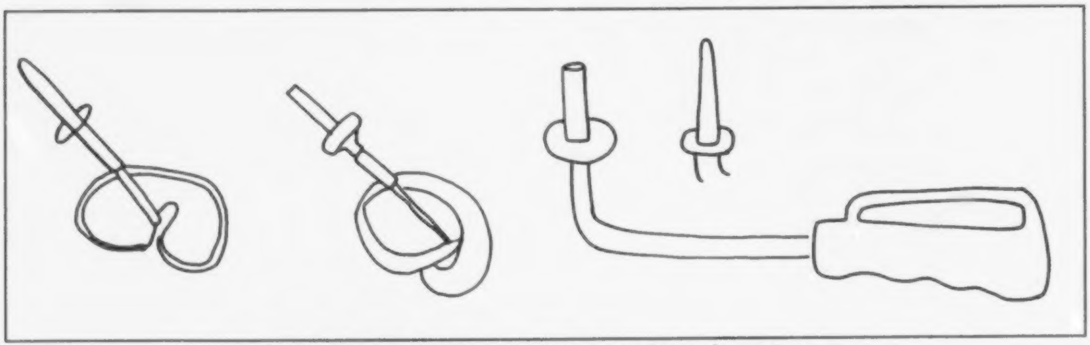
deluxe lever catheter clamp



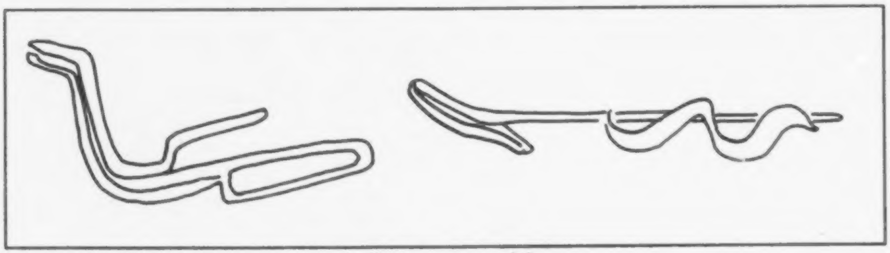
velcro leg bag straps



e-z pull urinary drainage valve

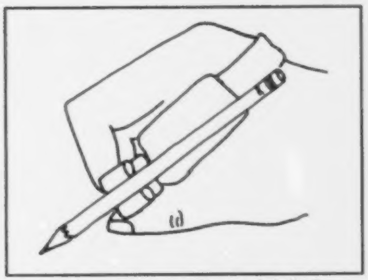


digital stimulators and suppository inserters

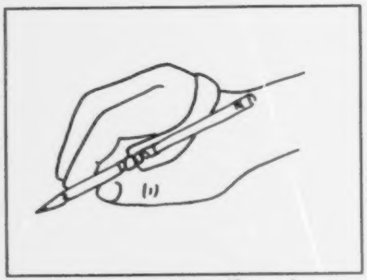


toilet paper aids

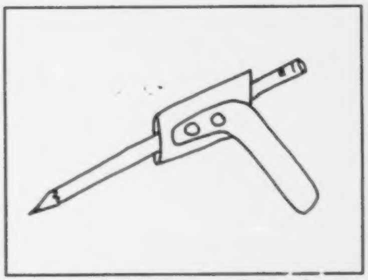
ADAPTIVE EQUIPMENT - COMMUNICATION



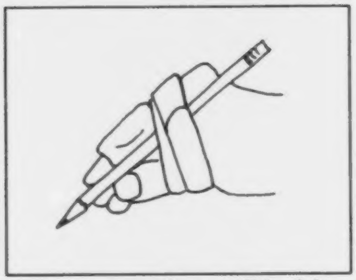
universal cuff and klick pencil holder



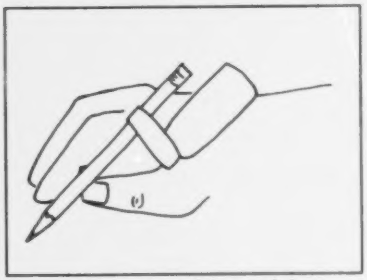
universal cuff and sidewinder pencil holder



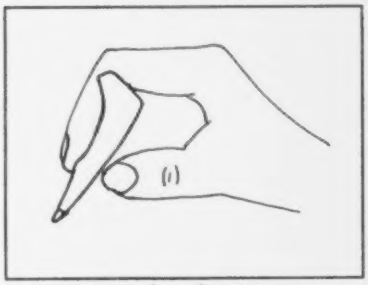
vertical holder - slides into universal cuff



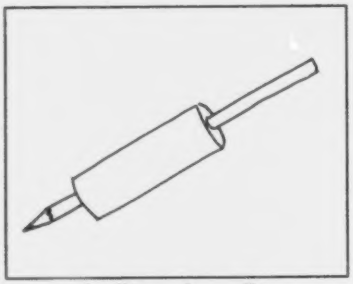
wrap around pencil holder



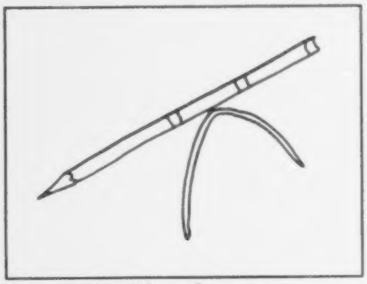
slip on writing aid



quad-quip pen

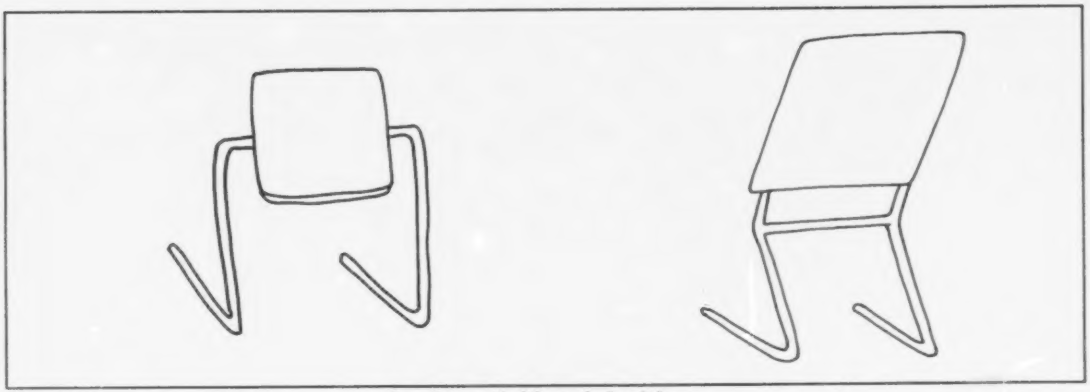


built up handle

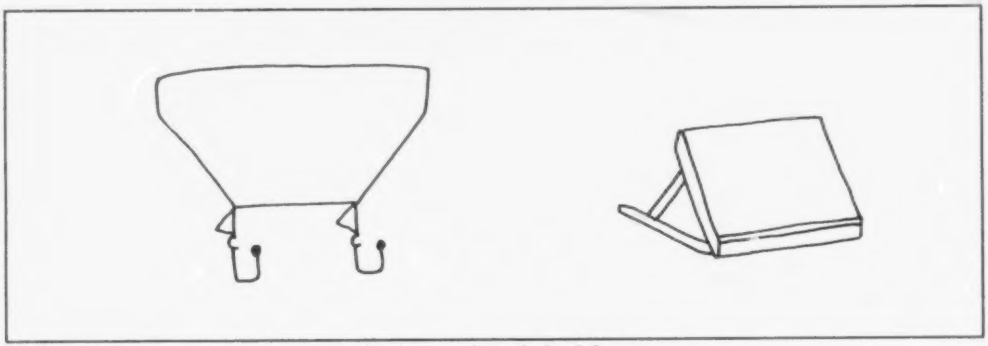


writing frame

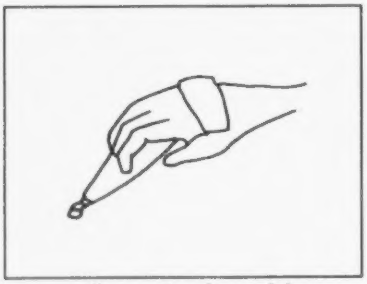
A clipboard may be used to stabilize paper if you can't hold it with your other arm.



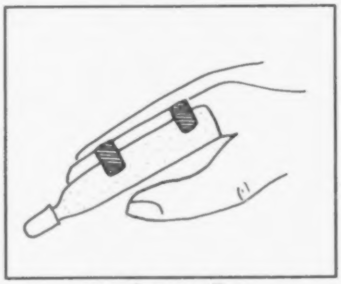
bed model book holders



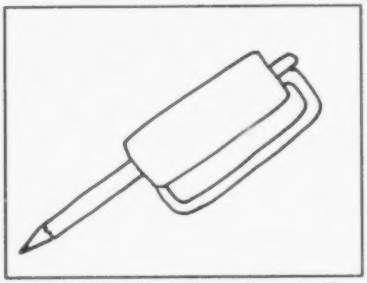
desk top book holders



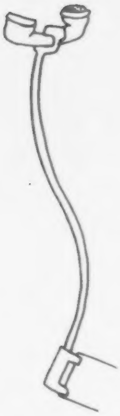
slip on typing aid

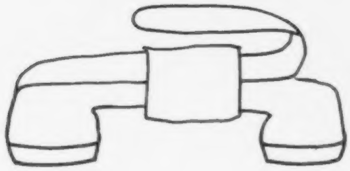


typing splint



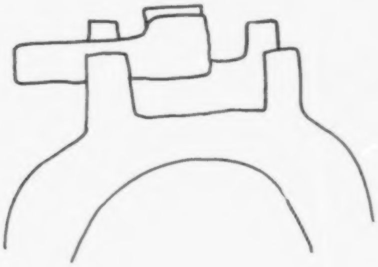
universal cuff and pencil





phone holder-may make a handle from plastic or metal and tape to the receiver

phone holder-receiver on gooseneck holder that can be positioned where convenient.



Phone flipper - holds connect button down. Use in conjunction with phoneholder

Visit stores that sell telephones to practice operating different types of phones. Speaker phones and automatic dialing may be convenient features.

WHEELCHAIR CUSHIONS

A good wheelchair cushion is essential for providing pressure relief. It helps distribute your body weight evenly over the wheelchair seat. There are many types of cushions available. You therapist will work with you to decide which is best for you. The decision should be based on factors such as the amount of pressure relief the cushion gives you, how the cushion feels to you, your balance and sitting posture, how you do transfers, your ability to perform independent weight shifts, climate where you live, cost, durability, weight of the cushion, continence, your skin condition, and personal preference.

In general, cushions are made from four materials: high density foam, air, gel, and water, or a combination of these materials. Life expectancy varies by type of cushion and the use and abuse it receives. As a cushion ages, it may lose its ability to distribute weight evenly. Cushions should be replaced as soon as they begin to wear out.

To assure good skin condition, you should also do the following:

1. If an air cushion is used, check daily to see that it is filled correctly.
2. Use only manufacturer recommended covers for the cushion.
3. Never use rubber air rings or doughnuts as cushions. They block the flow of blood to the skin inside the ring, acting as a tourniquet.
4. Make sure the wheelchair footrests are adjusted to the right height for you. If in doubt, too low is better than too high, since more weight will be distributed on the thighs, and less on the ischia (sitting bones).
5. Sit up straight in your chair. Slumping may cause pressure over the end of your tailbone. *(See the section on proper posture in Chapter 3.)*
6. Perform weight shifts regularly to relieve pressure on the skin.
7. Don't drag or slide your hips when getting in and out of the wheelchair, as this may cause bruises. Lift your hips when transferring to and from the wheelchair.

CHAPTER THIRTEEN

RECREATION THERAPY

IN THIS CHAPTER YOU WILL LEARN:

- What activities are available in Recreation Therapy.
- What is the value of Recreation Therapy.
- Some Community agencies where you may find recreation opportunities.
- Some organizations that can help you with your recreation interests.

RECREATION THERAPY

Recreation Therapy (RT) is an important part of the rehabilitation program at Shriners Hospital. After finding out about your interests and abilities, the recreation therapist will set up a plan with you to do some things you will enjoy. You may need adaptive equipment, or to learn some new games. You may want to develop a new skill or interest, or attend a special event such as a ball game or concert.

Keep in mind that in addition to offering a break from your busy hospital schedule, Recreation Therapy is a chance for you to try some new activities that you might like, not only while you are here but also after discharge. Even if you did not enjoy an activity before your injury, you are encouraged to try it at least once and give it a chance. By having an open attitude about trying new things, you give yourself a better chance to find some activities you will really enjoy.

After SCI you may fear that you will not be able to find enjoyable activities with your disability. Try to remember that there are many ways to have fun. If you are willing to grow and change, you will find there are ways to enjoy yourself and express your creativity even with your injury.

Following are several of the recreational activities available in our program. If you have a special interest which is not mentioned here, be sure to talk with the recreation therapist about it. The therapist will make every effort to find ways for you to pursue your interests.

Maija Hughes

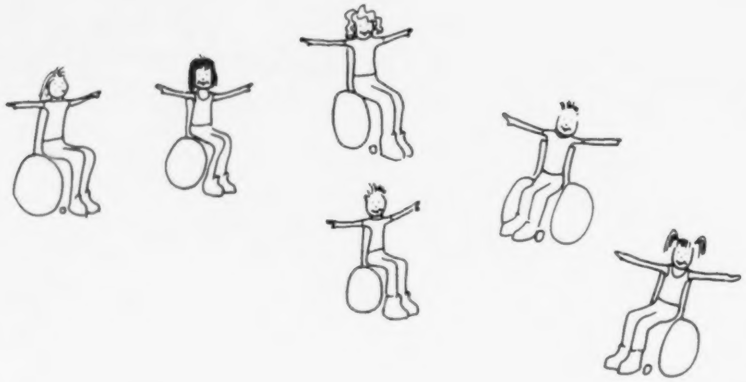
"The staff told me not to worry about relationships. I was pretty concerned about that since before my accident I dated a lot. They turned out to be right. It doesn't happen over night, but if you try to be an "up" person, you're going to attract people. You are also going to have a lot of fun!!...You need to get out and mingle. You need to be comfortable with your new situation. And - for God's sake - have a good sense of humor!!!

"..You better appreciate your recreation therapist and go to his 'get-togethers!' That's really important. You may feel tired or lazy, but go anyhow. It's important to learn to do things, play sports, swim. It's a step to getting back into the real world, whether you know it yet or not! Most of all - LAUGH!

Maija was 17 when she underwent several surgeries and rehabilitation at Shriners Hospital for her T-12 spinal injury. She has plans to go to broadcasting school and be a disc jockey.

PHYSICAL ACTIVITIES

An exercise class is held twice a week. This is a chance for you to move to music in a relaxed environment outside of therapy. This class is a lot of fun and guaranteed to get your blood flowing!



Swimming is available and is almost always enjoyed by our SCI patients. The recreation therapist takes one person at a time and works closely with you in the pool. The water helps many people move more freely and you may be able to do things in the pool that are difficult otherwise.

Trips to the bowling alley are organized every so often and you will be shown how to bowl in your wheelchair. This is a good chance to get out and have some fun.

ENTERTAINMENT

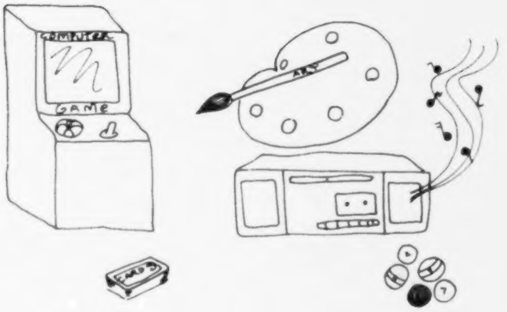
Video movies are shown about once a week and are available at other times. A variety of special programs and parties are given on holidays and periodically throughout the year for your entertainment. Civic leaders, celebrities, and sports stars have been known to visit, too!

OUTINGS

There will be opportunities for you to go on outings to the park, the zoo, sports events or restaurants while you are here. Such activities are planned according to the interests and abilities of the patients.

In addition to being fun, outings offer a valuable opportunity to learn how to manage out in public and get used to functioning in your wheelchair.

ARTS AND CRAFTS



The RT Department has a wide variety of art supplies and tools for those who enjoy doing artwork or crafts. You are encouraged to join in crafts projects and try out different artistic media. If you want some supplies we do not have, just ask. We can usually get them for you.

GAMES

Board games and card games are a great way to get to know other people and have some competitive fun. We have some video and computer games too, for electronics fans.

There are table games such as billiards and table tennis in the Recreation Therapy Department.

AFTER DISCHARGE

Discharge from a rehabilitation program is a big step. You will be leaving the protective and understanding environment of the hospital, where everything is set up for your convenience, and returning to the outside world, which may seem pretty scary and unfriendly at first. You will have a lot of adjustments to make in your first few months at home. One problem you may face is finding interesting leisure activities that are accessible in your wheelchair. We hope your experiences in Recreation Therapy will give you some ideas about things you will be able to enjoy.

In most communities there are a variety of organizations and facilities which offer a program of social and recreational activities. Make a point of trying out some of these opportunities. Doing something fun with others or pursuing a hobby can really help to keep your spirits up during this time and let you know you are not alone in the world.

Here are a few suggestions of places to go and people to contact about leisure opportunities in your community.

CENTERS FOR INDEPENDENT LIVING

These agencies exist in many cities to provide services to the disabled. They are an important source of information and support in every area of life. They may provide recreational programs through their office, or they will know about opportunities in your community. Use them!

SCHOOLS AND COLLEGES

Local schools offer access to special interest clubs, study groups, classes and events of all kinds. Adaptive physical education classes designed specifically for disabled people may be a good place to start in looking for contacts and opportunities. If there is no disabled students program, call the physical education department or the recreation director of the school.

PARKS AND RECREATION (P&R) DEPARTMENTS

Most cities and counties have a P&R Department which can give you information about nature activities, outings and outdoor recreation opportunities in your community. They may have a recreation therapist whose job it is to assist the disabled in their leisure pursuits. Ask!

CHAMBER OF COMMERCE

Almost every community has such an office, which can give you information about points of interest in your town, clubs and organizations, community events, and accessibility of buildings and transportation.

SERVICE ORGANIZATIONS

YM/WCA or YM/WHA, Scouts, Red Cross, 4-H and other community organizations and youth groups offer many options you may enjoy.

CHURCHES

Most churches offer a variety of social and recreational activities as part of their program. If you like to sing, try out for the choir!

COMMERCIAL RECREATIONAL BUSINESSES

Health spas, camps, theaters, amusement parks, and other commercial enterprises are often happy to cooperate with your special needs if you can pay for their services.

LOCAL RECREATION THERAPISTS

Ask at local hospitals or rehabilitation facilities if they have a recreation therapist. He or she will usually be glad to help you with information, advocacy, and direct support when possible.

SPECIAL GROUPS SERVING THE DISABLED

There are hundreds of organizations which have been formed by and for disabled people who share a special interest or need. Included here is a partial list of nationally based groups. By contacting them, you can connect with others and find out about chapters and activities near you.

National Wheelchair Athletic Association (Track&Field and more)
2107 Templeton Gap Road, Suite C
Colorado Springs, CO
(303) 632-0698

National Handicapped Sports and Recreation Association
Farragut Station (Sled skiing and others)
P.O. Box 33141
Washington, D.C. 20033

Canadian Wheelchair Sports Association
333 River Road
Ottawa, Ontario, Canada K1l 8B9

American Wheelchair Bowling Association
N54 W15858 Larkspur Lane
Menomenee Falls, Wisconsin 53051

National Foundation of Wheelchair Tennis
4000 MacArthur Blvd.
Newport Beach, CA 92660
(714) 851-1707

National Wheelchair Basketball Association
110 Seaton Building
University of Kentucky
Lexington, KY 40506
(606) 257-1623

Disabled Sportsmen of America Inc. (Hunting and More)
P.O. Box 5496
Roanoke, VA 24012

Handicapped Scuba Association
1104 Prado
San Clemente, CA 92672
(714) 498-6128

International Wheelchair Road Racers Club, Inc.
165 78th Ave NE
St. Petersburg, FL 33702

National Wheelchair Racquetball Association
c/o AARA
815 N. Weber, Suite 203
Colorado Springs, CO 80903

National Wheelchair Softball Association
P.O. Box 737
Sioux Falls, South Dakota 57101

North American Riding For The Handicapped Association
Box 100
Ashburn, VA 22011
(703) 471-1621

United States Quad Rugby Association
811 Northwestern Drive
Grand Forks, North Dakota 58201
(701) 775-0790

Wheelchair Motorcycle Association
101 Torrey St
Brockton, Massachusetts 02401

Wheelchair Pilots Association
11018 102nd Ave N.
Largo, FL 33540
(813) 393-3131

Association of Handicapped Artists
1134 Rand Building
Buffalo, N.Y. 14203

Handicapped Travelers Association
1291 East Hillsdale Blvd.
Foster City, CA 94404

Minnesota Outward Bound School Program for the Disabled
308 Walker Ave
South Wayzata, Minnesota
(612) 473-5476

Courage Center (Camping and Hiking)
P.O. Box 697
Breckenridge, CO 80421

RECREATION CHECKLIST

Name three places in your community you could go to find accessible leisure activities.

What are the recreational or leisure interests you would like to pursue once you leave the hospital? Do you need support or help to do that?

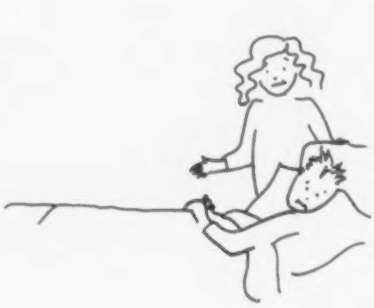
CHAPTER FOURTEEN

SOCIAL SERVICES

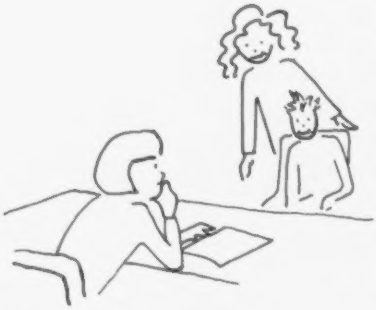
IN THIS CHAPTER YOU WILL LEARN:

- How the Social Worker can be of assistance.
- About some feelings you may be experiencing.
- How to find Community Resources.

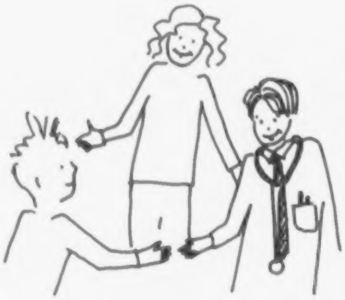
SOCIAL SERVICES PROVIDES



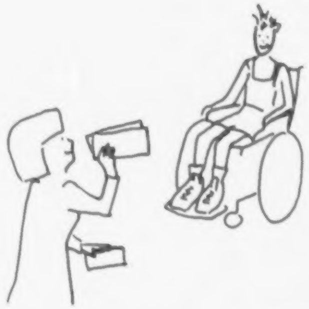
Support in coping with the stress that can go with difficult medical diagnoses or treatments.



Counseling and guidance by talking over problems and helping find solutions.



Help in communication among patients, family and members of the health care team.



Assistance locating the appropriate resources for help with practical concerns.

BEST COPY AVAILABLE

SOCIAL SERVICE PROGRAM FOR PATIENTS AND THEIR FAMILIES

Social Services is an important part of the SCI Unit Rehabilitation program. The social worker will meet with you and your family soon after your admission. It is very important that your parents, brothers and sisters attend these meetings. This gives the social worker a chance to get to know you and your family so that she can plan with you all for making your stay here a good one as well as helping with plans for your return home. The social worker will meet regularly with you and your family (or contact your family by telephone if in another state or country) throughout hospitalization to help you cope with the feelings you have about your accident and paralysis, your hospitalization, and your plans for going home.

All of the teen-age patients on the SCI Unit attend the weekly Support Group, facilitated by the social worker. Here patients can help each other as they get used to the changes in their lifestyle and as they plan to go back to home, school and friends. You have a lot of good ideas to share with each other since you have all experienced an important event; being teen-agers who have just had an accident and spinal cord injury.

As you plan for discharge, the social worker will work with you and your family. The feelings and concerns you have can be explored together. Information on financial assistance, attendant programs and other programs in your local area can be provided. You will get a follow-up phone call from the social worker after you are home for a few weeks; this will be a chance for you to ask any questions that come up for you after discharge.

At any time during your stay at Shriners, you or your family are welcome to talk with the social worker. The Social Services Department is here for you!

DEALING WITH THE CHANGES

You've made it this far! Through an accident, surgery, and a rehabilitation program. You are on your way back home, but on a road that you never expected to travel.

There's been a change. A spinal cord injury brings a big change to the way your body works and you have a lot of feelings about that. This is new, unfamiliar and uncomfortable at first. Maybe you can't believe this has happened to you or perhaps you don't want to believe it. Maybe you're angry at the others involved in the accident, at yourself, your parents or God. You might cry more, yell more, or feel more depressed. After an injury, you feel sad that old abilities are gone; old familiar ways of doing things are lost. You might feel your whole life has changed. It's hard to begin new things. You feel slow and uncomfortable trying new movements. Maybe you fear that you'll never be happy again. You may feel that if you cry or feel mad, sad, or scared about the injury that you'll never stop feeling that way.

But...just the opposite is true! You don't have a choice about what feelings you find inside yourself - you just feel them. You do have a choice about what you do with those feelings. You can try to push the anger and fear away, by distracting yourself or refusing to talk about the feelings you have; but the feelings don't really go away. The fears, anger and sadness will stay inside and pop up when you are home alone or in bed at night or sitting quietly in a classroom.

Let your feelings out! Then you will have room inside to experience happier things. It's important to acknowledge all of the feelings that you have about your accident. Talk with yourself, a friend, your family. You'll need to do this many times because you have been through such a big change that you were not expecting.

Your family will have lots of feelings about your injury, too. It is important that the whole family talk together about this. Each of you is experiencing an important event - a change in the life of one of your family members - you. If you let each other know how you are feeling and what the difficulties are, then, together you can come up with ways of adjusting to the changes in your life.

BECOMING INDEPENDENT

SCHOOL BOOK

One of the most important changes that goes on during adolescence is the process of becoming independent physically, emotionally, socially and financially from your parents. More often than not, this is a difficult process, as you balance the need for your parents' support with wanting to make your own choices. It can be rough for parents too, who try to balance concern and protective feelings with the desire to see their children grow and spread their wings.

A spinal cord injury can seriously disrupt this process. Suddenly the independence you cherish and strive for is gone, as you find yourself needing more care and assistance in many aspects of living. At a time when your family may already be in a lot of conflict about independence and responsibility, your whole life has been complicated by the limits imposed by your injury.

It is true that SCI will alter your lifestyle in some important ways. It is NOT true that you can never hope to achieve adult independence. Regardless of the extent of your injury, it will be possible for you to live independently and pursue adult goals of work and family life if you choose to. There are adults even with very serious disabilities out there doing it right now.

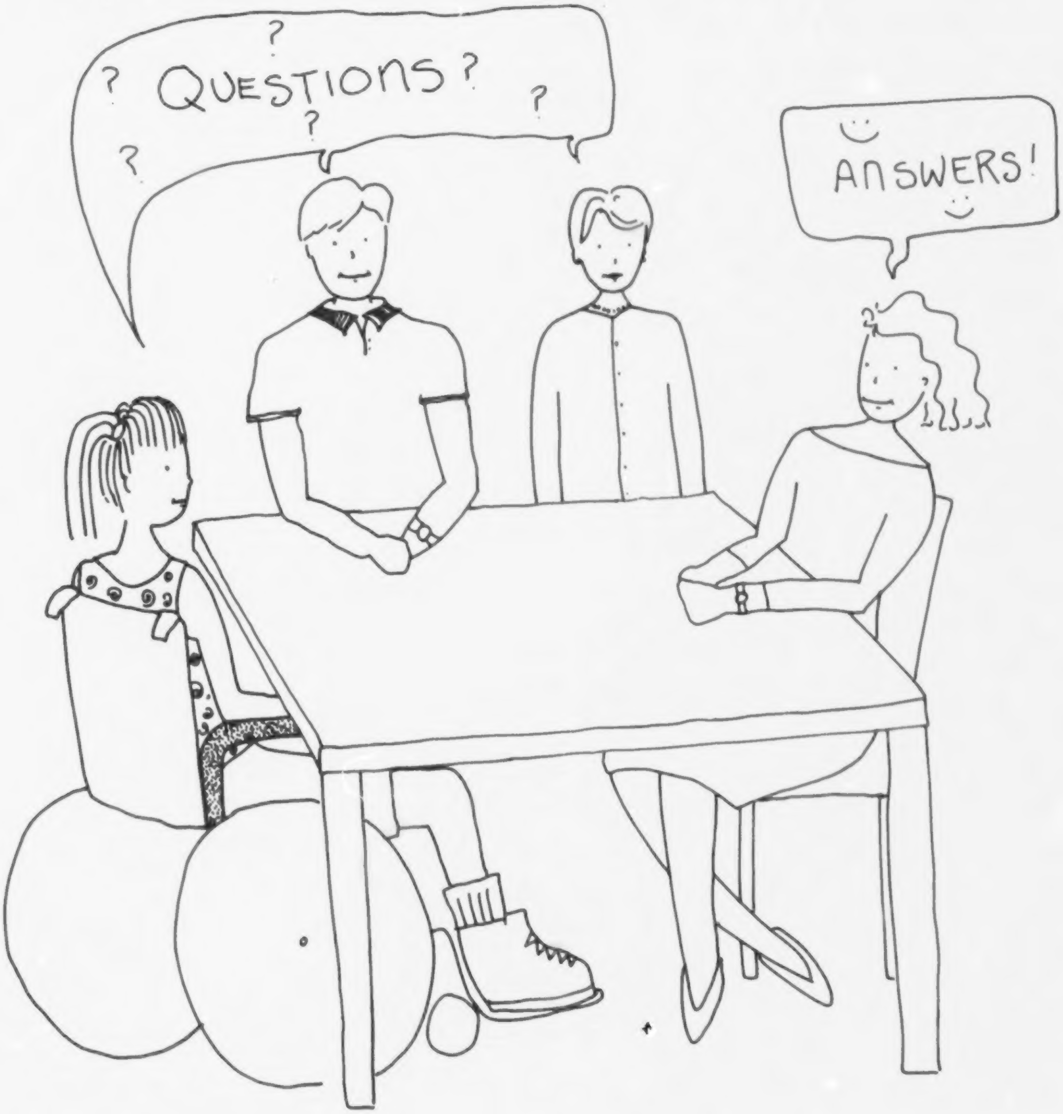
The fact is, the process of growing up and becoming independent is similar whether you are disabled or not. It may take longer, and be more complicated for both you and your parents. There may be financial issues to work out and changes in your educational plans or vocational choices. But there are organizations and agencies to help with these difficult issues. With determination and an organized approach, you will be able to continue to move toward independence even with a spinal cord injury.

Some ways to begin to regain power over your body and life are:

1. Get all the information you can about your injury and the care you need. Then you can make responsible decisions about your care.
2. Learn to communicate responsibly what you are thinking and feeling. Good communication skills will help you be more effective in life.

DISCHARGE

Once you are ready for discharge, another change happens. You'll move from the hospital back to your home. You'll probably have mixed feelings about that. You might be a little scared - "Will I be comfortable at home? How will my friends react seeing me in a chair? Will I ever have a boyfriend/girlfriend?" Leaving the hospital reminds you that paralysis is something you'll take with you everywhere you go. It will be important for you, your family and your friends to talk about how you are feeling about this. That way, you can help each other adjust to the changes and move on with your lives.


? QUESTIONS? ? ? ? ?
ANSWERS!

COMMUNITY RESOURCES FOR SPINAL CORD INJURED CHILDREN AND ADOLESCENTS

Handicapped Children's Program: Contact your local Department of Public Health to apply for this program. It will provide equipment and sometimes other medical care related to spinal cord injury.

Social Security Disability: Apply at your local Social Security Office. This program will provide monthly funds to all disabled children hospitalized for 30 or more days. Funding will continue upon discharge if family's income meets eligibility requirements. A disabled person may apply for this at age 18 years, and be reviewed for eligibility independent of the family income.

Center for Independent Living: These centers are set up throughout the U.S., under variations of this name, to assist the disabled person in maintaining an independent lifestyle in the community. Services vary and can include: referrals to attendants, referral to accessible housing, financial advising, peer counselling. See your local telephone directory or contact: Center for Independent Living, 2539 Telegraph Av., Berkeley, CA (415) 841-4776.

Office of the Mayor: Many times through this office you can get information on guides, bus service and other city-wide services available to persons with disabilities.

School District Office of Special Education: Contact your local school district offices to arrange for your child's return to school. Transportation, accessible school, home teachers etc. are arranged through this office.

Family Service Association of America and Community Mental Health Clinic (county services): These agencies provide low cost counselling to children, teen-agers, parents and families as they adjust to disability and other personal or family concerns. See your local telephone directory or call Shriners Social Services for assistance.

Sources of Information

National Spinal Cord Injury Association
149 California St.
Newton, MA 02158
(617) 964-0521
Has local chapters.

Office for Handicapped Individuals
Dept. of Health, Education and Welfare
388 D Hubert H. Humphrey Bldg.
Washington, D.C. 20201
(202) 245-1961

National Paraplegia Foundation
333 North Michigan Av.
Chicago, IL 60601
(312) 346-4779

Paralysis Project of America
111 Sutter St.
S.F., CA
(415)434-1514

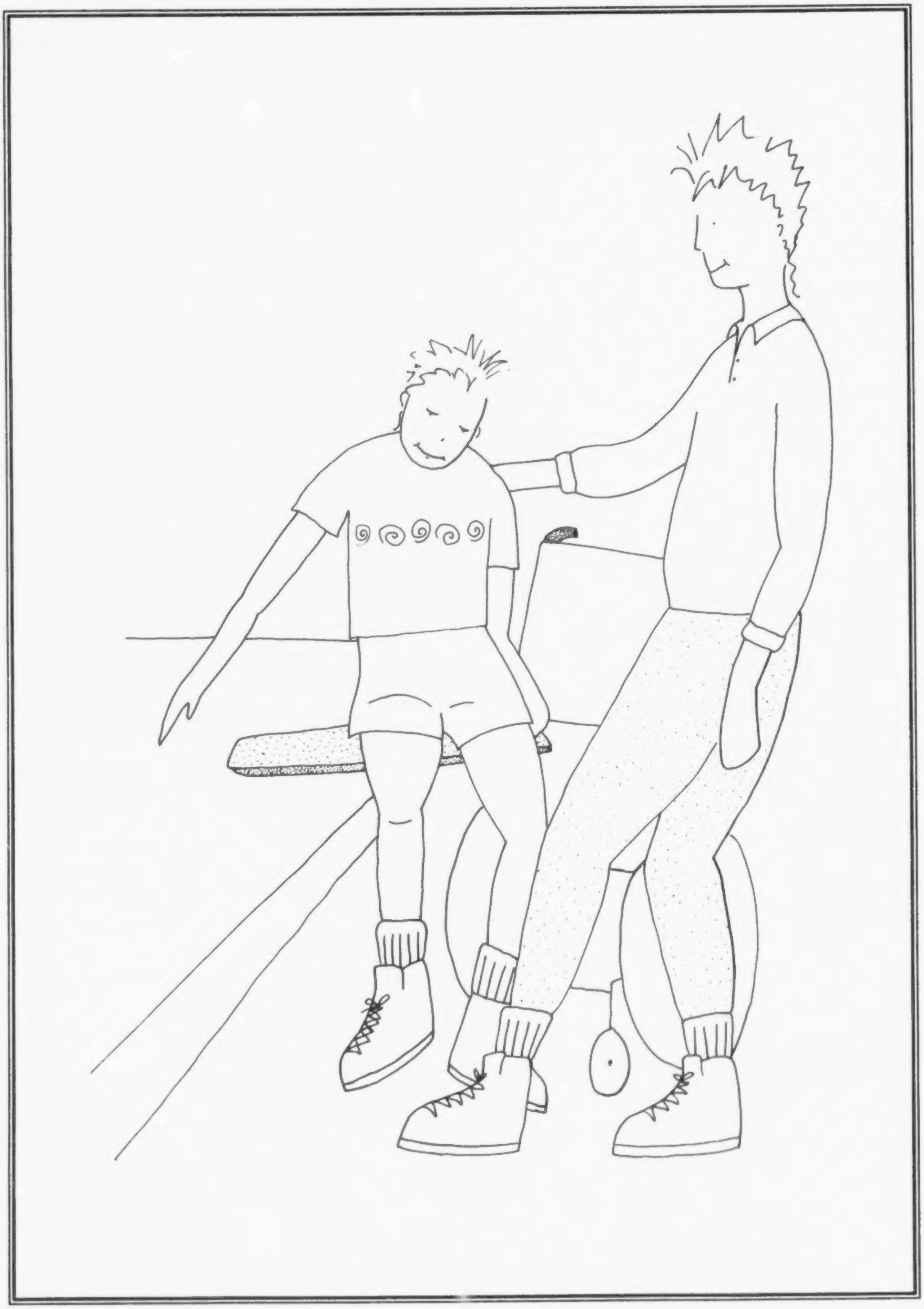
ASK YOUR SOCIAL WORKER FOR OTHER RESOURCES AVAILABLE IN YOUR HOME AREA.

CHAPTER FIFTEEN

ATTENDANT CARE

IN THIS CHAPTER YOU WILL LEARN:

- Ways to find Attendants.
- How to interview a potential Attendant.
- How to train your Attendant.
- Hints for keeping your Attendant.



ATTENDANT CARE

One of the facts of life after SCI is that you may be unable to do everything for yourself that you need in order to be comfortable, safe and independent. If you are a young person with a low injury still living at home, you may be mostly independent by the time you go home, and your family members may be able to provide all the help you need.

If you have a high injury, you will want to consider having an attendant even if your family members are available to do your daily care. Employing an attendant allows you to be independent of your parents for bathing, dressing, and grooming, as you were before your injury. It also makes it easier for your parents to maintain their proper role of setting limits, guiding and supporting you to live an independent life.

Hiring and managing attendants successfully requires some special skills and a good understanding of human nature. It is a good idea to start developing these skills now so that you can establish an effective system before it is time for you to live independently.

This chapter will explain how to find an attendant, how to interview and hire people, and how to set up a good working system with your attendant. It will help you to understand what your responsibilities are and what you can expect of others.

DECIDING WHAT CARE YOU NEED AND WANT

The Social Worker and SCI staff will help you decide how many hours and what kind of care you will need. You will also have to decide how much you can afford to pay and any personal requirements you may have in choosing an attendant. Make a list of the skills the attendant will need to have or learn and any other specific responsibilities you will expect of them. You will also be looking for qualities such as reliability, a positive attitude, and flexibility; be thinking about the type of person you and your family will want.

FINDING AN ATTENDANT

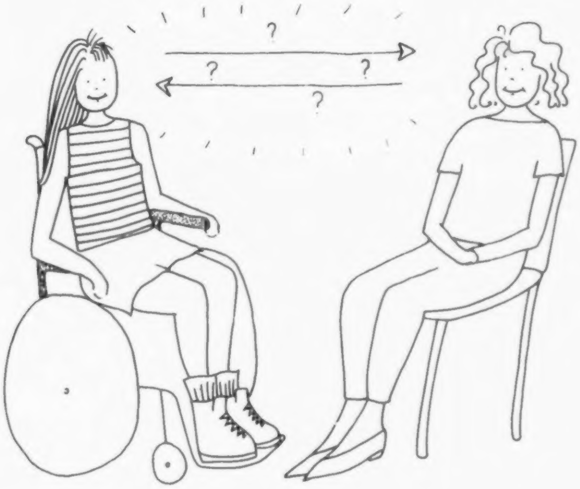
If you live in a city or large town, there are probably community organizations which can help you find an attendant. There may be a Center for Independent Living or a similar organization near you which can give you the names of people who are looking for such a job. They often screen and train attendants too, and can give you good practical advice on how to choose and work with an attendant.

In smaller towns or rural areas, you may have to look harder and farther to find the right person. Nearby hospitals and nursing homes, community colleges, churches and social service agencies should be contacted.

You may want to run an ad in the "Help Wanted" column of your local newspaper. Other disabled people in your community may know a good attendant or a good resource for finding one. You might look into the retired community. An older person may be more patient and reliable and may be happy for something to do.

SCREENING BEFORE THE INTERVIEW

Once you have some names of possible attendants, you will need to interview them. When you set up a time for an interview, get some information from each applicant. You will want to write down their full name, address and phone number, the names of several personal references and former employers. It is ESSENTIAL to check references and assure yourself that the person is trustworthy and reliable. Be sure your potential attendant is known and trusted in your community.



THE INTERVIEW PROCESS

You should interview the applicants yourself if at all possible, since you will be the one working with them. In the beginning, your parents may also want to be a part of the interview and decision process.

During the interview, you will obtain more information by asking questions which require an explanation rather than yes/no questions. For instance, say, "Tell me about your last attendant job," rather than, "Do you like working as an attendant?"

Just as important, you will want to get a feel for whether you can be comfortable with the person. Discuss your care needs frankly and see how they react. Observe whether they listen carefully and show genuine interest. An enthusiastic, responsive person with less experience, but who is willing to learn, may be a better attendant than a more experienced but closed-minded person who cannot take direction.

Discuss with your applicant how much you will pay them and what the work schedule will be. Be sure they have reliable transportation. Ask them about family, work or school obligations which might interfere with their availability. While it is natural for an applicant to feel a little nervous, they should be able to speak openly about their ability to do the job. Be sure to give them a chance to ask questions too. This will tell you a lot about what is important to them.

Don't hire an attendant just because you like them. It is great if you become friends with your attendant. But more important is their ability to assist you in a safe and reliable manner. Remember your relationship is primarily a working relationship, not a social one.

AFTER THE INTERVIEWS

After you have chosen an attendant, both of you should sign a written contract specifying the terms of your agreement, and each of you should keep a copy. This will help prevent any misunderstandings later about wages, hours, or job responsibilities. If by mutual consent you change the agreement, the contract should be changed too.

Call the other applicants back and thank them for their time. Ask them if they would be available in the future if you need another attendant. It is a good idea to keep a list of back-up names in case your first choice does not work out. Try to stay on good terms with as many qualified people as possible. You may need them someday.

TRAINING YOUR ATTENDANT

While you are still in the hospital, you need to learn the specific details of each step of your care. It will be up to you to teach others what you cannot do for yourself.

Learn to describe each step clearly. Learn the names of your equipment and supplies and practice telling others how to use them.

When teaching a new attendant, have this manual or other written instructions available for them to study. Ideally, the new attendant should have the chance to observe each procedure being done correctly by someone else. If this is not possible, allow extra time for careful explanations and mistakes.

Do not expect an attendant to learn everything in one day. You may need to talk them through the procedures several times before they feel comfortable with them. Encourage them to ask questions and reassure them that it will soon come more easily. A little praise will help them gain confidence and learn more quickly than will impatience and criticism.

KEEPING YOUR ATTENDANT

Many people who take this kind of work will be doing it temporarily, while they are going to school or until they can find a full-time job. So you should not take it personally if people quit from time to time.

However, there is much you can do to make the job easier and more attractive so that you can keep your attendant longer. If you are a fair and considerate employer, you have a better chance of attracting and keeping a good attendant who will be loyal and reliable.

Along with wages, the most important aspects of a job for most people are being treated with respect and finding some satisfaction in their work. You can do a lot to provide these for your attendant.

Cultivate an attitude of kindness and respect with your attendant. Always be fair and let them know you appreciate their efforts. Talk about the positive aspects of your life as well as your needs and problems. Show some interest in them, their family, their problems or goals. Almost everyone will appreciate and respond well to this kind of basic caring.

Respect your attendant's time as much as you want yours to be respected. Be ready to work when they arrive and have the supplies you need. Do whatever you can for yourself. Let them know exactly what you expect, and if you need to correct them, do it in a gentle way. Most people want to please their employer and will accept correction more easily if it is given with consideration for their feelings.

Avoid giving too many instructions at once. This can confuse and frustrate your attendant. Once you see that the attendant knows your care, allow them to proceed and talk of other things.

Be sure your attendant has adequate time off and give them plenty of notice if your schedule changes. Do not expect them to work longer than agreed. If they must work overtime, pay them for the extra time. If you sense some dissatisfaction or upset, encourage them to talk about it. Some people will quit rather than confront an employer with a problem. Chances are a solution can be worked out if you can talk about the problem together.

In exchange for fair and respectful treatment, you have the right to expect reliability, honesty, and good communication from your attendant. It is better to express any dissatisfaction you may have immediately than to be silent and let your resentment build. Let the person know your limits regarding lateness, absence, poor performance, or any other issues that may present a problem. If the person is a good attendant, give them a chance to improve.

If the person cannot respect your limits, or if you find they are unreliable or untrustworthy, you may need to fire them. If possible, give them two weeks' notice. This will give you a chance to find another attendant and them a chance to find another job. It is better to find another attendant than to live with the irritation and uncertainly of working with someone who does not meet your needs.

Liane Yasumoto

Liane was attending City College when an auto accident left her a C-3-4 quadriplegic. After rehab at Shriners, Liane returned home and proceded with her plans to attend UC Berkeley.

Liane now is active in the UC Disabled Students Program and lives in a wheelchair accessible dorm near campus. She has had a variety of experiences managing the attendants she hires to help with her daily care.

"I found all my attendants through friends and word-of-mouth. Most of them have been students and I trained them myself. When I was at Shriners the therapists taught me how to instruct my attendants and that really helped. I'm very careful to teach them good body mechanics so they don't drop me or hurt themselves when they transfer me.

"In choosing an attendant, you have to have your priorities straight. It is very important that they are competent and on time. One attendant didn't seem very friendly or interesting when I hired her but she was very reliable and competent and we got along just fine. Another attendant was a good friend but she was late a lot, and it was hard for me to assert my needs with her because of our friendship. I wanted to fire her, but I couldn't. Finally she quit.

"If you hire someone you don't know, always check out their references. A disabled person I know got ripped off by his attendant when he gave them his ATM card. You must find someone you can trust."

CANINE COMPANIONS

Canine Companions for Independence (CCI) is an organization which trains dogs to serve as helpers for disabled people. The dogs provide such services as pulling wheelchairs, turning on lights, fetching dropped or out-of-reach articles, going for help in an emergency, and many other activities. They also provide companionship, loyalty, affection and an increased sense of confidence for many who might otherwise feel lonely and timid.

The dogs are provided free to qualified applicants, who must show initiative and a strong desire to be independent. They must be able to feed and care for the dog as well. People of all ages and all types of disability are eligible. Children as young as six years of age have received dogs through this program.

The applicant is taught to work with the dog in a special two-week intensive training course held at one of the CCI centers. During the two weeks, the applicants learn a great deal about dog psychology and training, and how to use the dog in performing everyday activities. In order to graduate, they must demonstrate mastery of the needed commands, teamwork and proper etiquette while out in public with their dogs.

If you are interested in finding out more about Canine Companions, we have brochures and articles in our library. Or you can contact CCI at the address below.

Canine Companions for Independence
P.O.Box 446
Santa Rosa, CA 95402-0446
(707) 528-0830

CHAPTER SIXTEEN

SEXUALITY

How you feel about being a male or female and how you relate to other people as a man, woman, boy or girl are all part of your SEXUALITY. After a spinal cord injury, people often have questions about how the injury may affect this aspect of their lives.

Will I be attractive to people if I am in a wheelchair? Will I be able to marry and have children? Can I fulfill my role as a sexual partner, or as a parent? What special needs might I have as the result of my injury? These and many other questions may have occurred to you since your injury.

While you are at Shriners Hospital, you will receive information which will help answer your questions about this important area of life. Each patient will be assigned a staff member who is specially trained to answer your questions and provide information appropriate to your age and interest. You are encouraged to keep any written materials they give you in this section of your Self Care Manual. You may find this a valuable resource after you leave the hospital.

As you get older, your questions and areas of interest may change. If you return to Shriners for further therapy, you can find out more about sexuality while you are here. Your staff advisor or therapist will also be able to recommend books, films, and other materials to help you find out what you want to know.

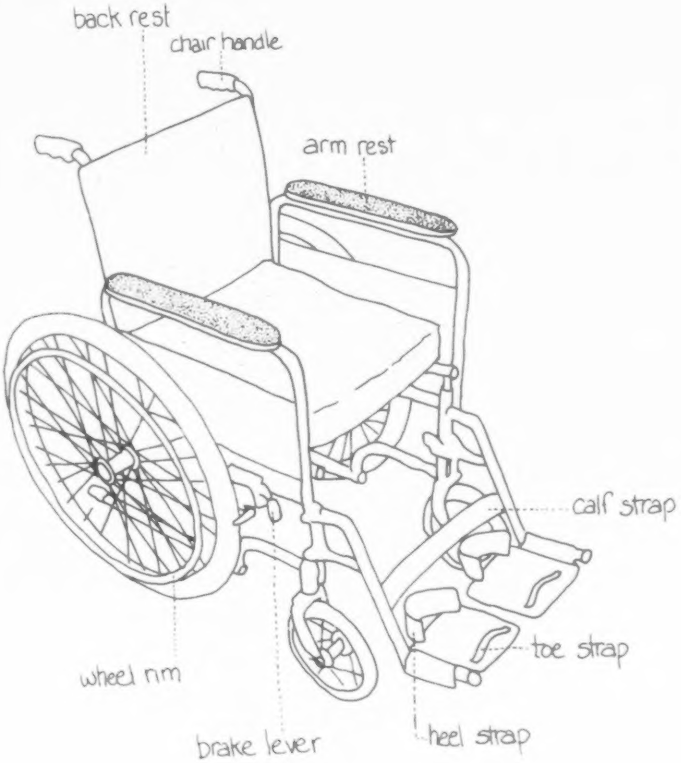
Appropriate information will be provided to the parents as needed. We encourage parents to ask questions and become well-informed so that they can be a reliable resource for their child.

CHAPTER SEVENTEEN

EQUIPMENT MAINTENANCE

IN THIS CHAPTER YOU WILL LEARN:

- The parts of your wheelchair.
- Some tips for maintaining your chair.
- How to care for elastic stockings, binders, and corsets.


back rest
chair handle
arm rest
calf strap
toe strap
wheel rim
brake lever
heel strap

THE WHEELCHAIR

Your wheelchair is a very expensive piece of equipment which will last for years if properly cared for, but which will break down if neglected or abused. It is important for you to learn wheelchair maintenance so you can prolong the life of your chair and make quick repairs if it breaks.

There are several different kinds of wheelchairs. While you are at Shriners Hospital, you and the staff will determine which kind of chair will be right for you based on your injury, your lifestyle, and your preferences. When you go home, you may be given a wheelchair to take with you.

Once you have your own chair, study the Owner's Manual carefully and learn how to maintain and repair your chair. Even if you cannot do the repairs yourself, you should be the one to keep track of routine maintenance and you should know how to trouble-shoot the most common problems. That way you will not be stuck at home if your chair breaks down.

If you use a manual chair, make a point of getting to know a local bicycle repair person who knows about wheelchairs. They will be able to help you with many problems. Electric wheelchair users should know how to get in touch with the vendor of their chair in case of problems.

Every type of wheelchair is different but some parts are basic to all chairs. These will be described here so that you can become familiar with the parts and how they are maintained.

UPHOLSTERY

This is the leather, vinyl, or cloth covering on the seat, back, and armrests of the chair. It should be kept clean and dry. Regular cleaning with a good leather or vinyl cleaner will prolong the life of those materials.

Upholstery will stretch eventually with daily use. For best posture and distribution of weight, replace worn or stretched upholstery. Some sports chairs have a built-in velcro adjustment for the seat. A leather strap across the back of your wheelchair will decrease sagging in that area.

BRAKES

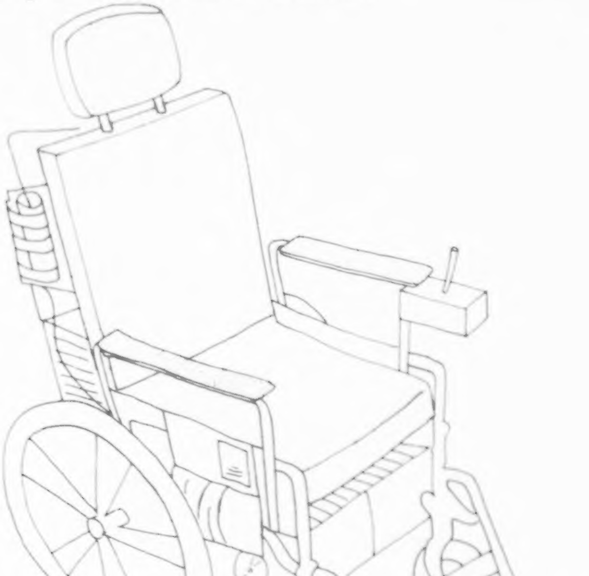
The brakes are an important safety feature because they keep the wheels from turning when you transfer or park on an incline. They will need to be adjusted at intervals. Brake adjustment is demonstrated on the Home Care Video, and there should be instructions in your Owner's Manual.

CUSHION

There are many types of wheelchair cushions; the therapy staff will help you decide which kind you should use. It is ESSENTIAL that you use your cushion whenever you are sitting, and that you replace it when it shows signs of wear. Along with weight shifts, your cushion is your main defense against pressure sores. Keep it clean and dry. If you have an air-filled cushion, maintain the proper air pressure in it to prolong its effectiveness.

BATTERY

An electric wheelchair uses a battery for power. It needs to be recharged every night, according to the instructions in the Owner's Manual. It should be hooked up to the battery charger as soon as you get into bed at night, so you never have to wake up to a dead battery and a useless wheelchair.



FRAME

The metal parts which support the chair are called the frame. This also needs to be kept clean and dry. Moving parts will need to be lubricated on a regular schedule. (See your Owner's Manual for specific instructions.)

WHEELS

The TIRES will last longer if kept at the proper inflation pressure. They need to be replaced when worn. Be sure to have a tire patch kit with you at all times, and know how to change a flat tire!!!!!

The BEARINGS are little balls in the wheel mechanism where the frame joins the wheel. They need to be lubricated and replaced when worn.

The SPOKES maintain the wheels in circular alignment. Spoke tension needs to be adjusted with a spoke tightening wrench, available at bicycle shops or through your wheelchair vendor. Get someone experienced to show you how to do this before attempting it yourself.

You might consider mag wheels as an alternative to spoked wheels. Mag wheels require less maintenance but are heavier.

The CASTERS are the small front wheels. If they are solid, they only need to be replaced when worn. If they are pneumatic (have air in them) you will need to keep them inflated to the proper pressure.

FOOTRESTS

Footrests support and protect your feet and should be replaced if broken. A drop of machine oil will keep the joints moving freely.

OTHER MAINTENANCE TIPS

Never use a regular chair for showering or submerge the chair in water, as when entering a ramped pool. Water will damage the upholstery and rust the bolts and hinges.

When cleaning your chair, first sponge or dust off the frame and upholstery. Dry all hinged parts. Keep wheel and caster axles free of hair, string or lint. Frequent cleaning will prolong the life of your chair. Do not use corrosive detergents.

Black rubber tires are less expensive, but they leave black marks on the floor, unlike grey rubber tires.

Check frequently that the seat belt is properly adjusted and located. Dangling straps and belts are easily caught in spokes, causing damage to both.

Velcro surfaces will remain adherent longer by keeping them free of lint and dust. This is done by brushing with a stiff wisk broom.

ELASTIC STOCKINGS

Elastic (TED) stockings should be washed often by hand in warm water with a mild soap. Roll in a towel to absorb extra moisture. Dry on a flat surface at room temperature. Do not wash or dry stockings by machine. Harsh detergents, bleach, cleaning fluid, scrubbing, wringing and ironing are harmful to the elastic and will greatly shorten their life.

BINDERS AND CORSETS

Binders and corsets should be washed by hand in warm water with mild soap as for elastic stockings. NEVER WASH OR DRY BY MACHINE!

Index

A

Abdominal Muscles 7-3
Accessory Muscles 7-3
Activity Attendance Rules 1-11
Adaptive physical education classes 13-5
ADL 12-2
AFO G-1
Alcohol 8-6, 9-11, 9-12, 10-4
Alcoholic beverages 5-7
Ambulation G-1, 11-8
Anus G-1, 5-3, 5-8
Appetite 6-9, 6-10
Attendant Care 15-3
Autonomic G-1
Autonomic Hyperreflexia 9-5
Autonomic Nervous System 2-4

B

Binders 17-7
Bladder 4-3, 9-5
  infection 4-5, 4-8
  stones 4-5
Bladder Program 4-4
Blood 8-3
Blood Vessels 8-3, 9-5
Bowel Problems
  Constipation 5-6
  diarrhea 5-7
  hemorrhoids 5-8
  impaction 5-7
  related to nutrition 6-2
Bowel Program G-1, 5-4, 5-5
Bowels 2-9, 5-3
Braces 2-13, 11-3, 11-10
Burns 3-3, 3-4, 9-8

C

Canine Companions for Independence 15-8
Catheter G-1
Catheterization
  Clean Technique 4-10, 9-11
Centers for Independent Living 13-5, 15-4
Cervical G-1
Circulation 6-9, 8-3, 9-7, 9-8, 11-8
Circulatory G-1
Circulatory System 8-3
Clean Technique 4-7, 4-10
Condom G-1
Condom catheter 3-12
Constipation G-1, 5-6, 6-5
Contracture G-1, 11-4, 11-8
Corsets 17-7
Crede G-1, 4-10
Cushion 17-4

D

Dairy Products 4-7, 6-6, 9-11, 9-12
Dehydration G-1, 6-8, 8-6, 9-11, 9-12
  related to bowel problems 5-7
Dermatome G-1
Dermatome Map 2-5
Dermis 3-3
Diagnosis G-1
Diaphragm 7-3
Diarrhea G-2, 5-7, 6-5, 9-12
Digital Stimuation G-2
Disabled students program 13-5
Discharge 13-5, 14-6
Dizziness 8-5
Dysesthesia G-2, 2-11
Dysreflexia G-2, 8-6, 9-5, 9-11, 9-12
  See also Complications
  supplies for tray 9-6

E

- Eating Plan 6-2
- Edema G-2, 6-7, 8-4, 8-5
- Elastic Stockings 8-4, 9-6, 9-7, 9-8, 9-12, 17-7
- Epidermis 3-3
- Equipment 11-10, 13-2
- Examination
  - urinary 1-5

F

- Fats 6-7
- Fiber G-2
- Flaccid Bowel G-2, 5-4
- Fluids 5-6, 6-8, 8-6, 9-11
  - drinking enough 4-6
  - limit 4-6
- FNS 2-13
- Food Guidelines
  - to keep urinary system healthy 4-7
- Frankel Classification System 2-9
- Fruits 6-5

G

- Gait Training 11-8
- Gastro-colic reflex G-2, 5-5
- Genitals G-2, 2-9

H

- Heart 8-3
- Hemorrhoids G-2, 5-6, 5-8
- Heterotopic Ossification G-2, 9-15
- Home Evaluation 12-2
- Hoyer Lift 11-6
- Hyperesthesia G-2, 2-11
- Hypodermis 3-3

I

- ICP G-2
- Impaction G-2, 5-4, 5-6, 5-7
- Incontinence 3-4
  - bladder 4-4
  - bowel 5-4
- Independent 11-3, 11-5, 15-3
- Ingrown toe nail 3-12, 3-13
- Intercostal muscles 7-3
- Intermittent Catheterization Procedure 4-10
- IPPB 7-6

K

- Kidney 4-3, 9-10, 11-8
- Kidney Disease
  - See also Complications
  - Signs of 4-8
- Kidney Failure 9-11
- Kidney Problems 9-10
- Kidney Stones 9-11

L

- Level of Injury 2-8, 11-7
- Lower Motor Neuron 2-10, 11-3
  - effects on the bowel 5-5

M

- Medications 10-3
- Mobility 11-5

N

- Nerves
  - Motor 2-4
  - Sensory 2-4
- Nutrients 8-3

O

- Oils 6-7
- Osteomyelitis 9-13
- Outings 13-4
- Overweight 6-9

P

- Padding 3-10
- Parallel Bars 11-8
- Paralysis 2-8, 2-12
- Paraplegia 2-8
- Patient Responsibilities 1-13
- Patient Rights 1-12
- Percussion and Postural Drainage 7-5
- Peristalsis 5-3, 5-4, 5-5
- Phlebitis 9-7
- Pitting Edema 8-5
- Positioning 3-9
  - proning 3-9
- Postural Hypotension 8-5, 9-11
- Pressure Sore 3-4, 3-6, 9-6
- Pressure Sores 9-13
- Prone 9-14, 11-4
- Protein 4-7
- Protein Foods 6-3
- Pulmonary Embolism 9-9

Q

- Quad cough 7-4, 7-5
- Quadriplegia 2-8

R

- Range of Motion 8-6, 9-15, 11-4, 12-2
- Recovery after SCI 2-12
- Recreation Therapy 13-2
- Rectum 5-3, 5-4
- Reflex 2-6, 2-10, 2-11
  - Gastro-colic 5-5
- Reflux 9-11
- Rehabilitation 1-4, 11-3
- Renal Calculi 9-11
- Respiratory System 7-3

S

- Sacral Sparing 2-9
- Salt 6-7, 4-7, 8-4
- Schedule 1-9
- Sclerosis 8-6
- Scoliosis 9-16
- Secretions 7-4, 7-5
- Sexuality 15-0
- Skin 11-8
- Skin Care 3-12, 8-4
- Social Worker 1-7, 14-2
- Spasms 2-6, 2-11, 3-9, 5-6, 11-8
- Spastic bowel 5-4
- Special Groups Serving the Disabled 13-7
- Sphincter 4-3
  - rectal 5-3, 5-8
- Spinal Cord 2-3, 2-6
  - injury 2-7
- Spinal Fusion 9-16
- Spinal Shock 2-8, 2-11, 4-4, 11-8
- Spirometer 7-6
- Starches 6-4
- Stones 4-5
- Stool 5-3
- Sugars 6-7
- Swimming 13-3

T

- TED Stockings
  - See elastic stockings
- Tests
  - Diagnostic 1-8, 4-4
- Therapist
  - Occupational 1-7
  - Physical 1-7
  - Recreation 1-7
- Thrombophlebitis 9-7
  - treatment 9-8
- Thrombus 9-7
- Transfer Board 11-6
- Transfers 11-6
  - assisted 11-6
  - dependent 11-6
  - equipment 11-6
  - independent 11-6
- Treatments
  - Functional Neuromuscular Stimulation . . . .

U

Ulcers . . . 6-11
Underweight . . . 6-10
Unit Policies . . . 1-10
Upper Motor Neuron . . . 2-10, 11-3
  effects on the bowel . . . 5-5
Ureters . . . 4-3
Urethra . . . 4-3
Urinary Reflux . . . 4-5
Urination . . . 4-3
  effect of SCI . . . 4-4
Urine
  normal appearance . . . 4-7
Urologist . . . 4-4, 9-10, 9-12

V

Vegetables . . . 6-5
Venous Stasis . . . 9-7

W

Water . . . 6-8
Weight Shifts . . . 3-6, 3-7, 9-14
Wheel Pegs . . . 11-7
Wheelchair
  battery . . . 17-4
  brakes . . . 17-4
  cushion . . . 3-10, 3-13, 9-14, 12-18, 17-4
  electric . . . 11-7, 17-3
  footrests . . . 17-5
  frame . . . 17-5
  manual . . . 11-7, 17-3
  upholstery . . . 17-3
Wheelies . . . 11-7

GLOSSARY

AFO's - Ankle-foot orthoses - Molded plastic supports used to maintain proper alignment of ankle and foot.

Ambulation - Walking, with or without braces, crutches, walker, or other devices.

Anus - The muscular opening of the lower bowel where the feces (food wastes) are expelled from the body.

Autonomic - The part of the nervous system which controls many automatic or involuntary activities of the body such as digestion and blood pressure.

Bowel (Program) - The bowel is the large intestine or colon. A bowel program is a procedure for emptying the bowel at regular intervals to avoid incontinence or impaction.

Catheter - A thin rubber tube used to drain urine from the bladder.

Cervical - The section of the spine in the neck area; the first seven vertebrae and the first eight spinal nerves.

Circulatory - Refers to the circulation of blood and the organs which circulate the blood, namely the heart and blood vessels.

Condom - A rubber sheath which fits over the penis. Used with a drainage bag to contain urine when there is loss of control of urination.

Constipation - Sluggish action of the bowels. Stool is hard, dry; bowels may not move for several days. Usually caused by lack of fluid and fiber in the diet, or because of lack of tone in the bowel.

Contracture - Permanent contraction of a muscle due to spasm or paralysis.

Crede - Pressure is applied to the lower abdomen to help empty the bladder.

Dehydration - Dried out condition resulting from excessive loss of body fluids.

Dermatome - A segment of the skin connected to one sensory spinal nerve.

Diagnosis - The use of scientific methods to determine the cause and nature of a person's illness or injury.

Diarrhea - Frequent, watery or very loose bowel movements.

Digital Stimulation - A gloved finger is used to stimulate the anus. This causes increased peristalsis and relaxation of the rectal and anal sphincters, producing a bowel movement.

Dysethesia - Abnormal sensation on the skin, such as of pins and needles, or of pain without outside cause.

Dysreflexia - (Autonomic Hyperreflexia) A condition seen in persons with high spinal cord injury. An irritation below the injury triggers a massive nervous and circulatory reaction, high blood pressure, slow heart rate, headache and other symptoms.

Edema - Excess fluid collects in the body tissues, producing swelling.

Fiber - (Dietary) The indigestible portion of foods; promotes smooth bowel movements and regularity.

Flaccid Bowel - The muscles of the bowel and anus are relaxed and peristalsis is reduced. Occurs in lower-motor-neuron injuries.

Gastro-colic Reflex - Increased colon peristalsis caused by the presence of food in the stomach.

Genitals - Refers to the reproductive organs: Penis, testicles and related structures in the male. In the female, the external genitals are the labia, clitoris, and vagina; internally, the uterus, ovaries, and related structures.

Hemorrhoids - Enlarged veins around the anus; usually caused by hard stool or rough handling of the anal tissue.

Heterotopic Ossification (H.O.) - Abnormal development of bone tissue in the soft tissues around a joint.

Hyperesthesia - Increased sensitivity to stimulation; often present in areas of the body at or above the spinal cord injury.

ICP - Intermittent Catheterization Program - A catheter is inserted into the bladder at regular intervals to empty urine from the neurogenic bladder.

Impaction - Hard stool collects in the bowel and cannot be passed by ordinary measures. May require enemas or (rarely) surgery to relieve blockage.

Incontinence - Inability to hold in urine or stool, resulting in an "accident."

Infection - Disease caused by growth of damaging organisms such as viruses, bacteria or fungi in the body.

Lower Motor Neuron - Part of the chain of motor nerves which extends from the brain to the muscles. The Lower Motor Neurons extend from the spinal cord to the muscles. Damage to these nerves results in absence of tone or reflex activity in the affected muscles.

Lumbar - The section of the spine in the waist area. (Mid back region.) The spinal nerves extending from these vertebrae.

Mobility - Another word for movement or ability to get around.

Motor - Refers to movement, such as in "motor nerves."

Neurogenic - A condition related to the nervous system. Neurogenic bladder is a bladder which functions abnormally because the nervous connections between the bladder and the brain are interrupted.

Neuron - A nerve cell or fiber.

Nutrients - Substances in food which are needed by the body for growth, movement, and other functions.

Osteomyelitis - Infection in a bone.

Paralysis - loss of voluntary muscle activity.

Paraplegia - Paralysis of lower portion of the body and both legs.

Peristalsis - Wavelike muscular contractions of the walls of the bowel, which serve to move the stool down and out of the body.

Postural Hypotension - Decrease in blood pressure with a change in position. Can result in dizziness, nausea or fainting in extreme cases.

Pressure Sore - An opening or ulcer in the surface of the skin caused by excess pressure. Also called bedsore or decubitus ulcer. May start as a closed area that appears discolored, warm or hard.

Prone - Lying on the stomach. Good for the skin and joints.

Pulmonary - Refers to the lungs and breathing.

Pulmonary Embolism - Obstruction of the pulmonary (lung) artery, usually by a clot from a leg vein. A very rare but potentially fatal complication of SCI

Quadriplegia - Paralysis of lower and upper part of body, including all or part of arm use.

Range of Motion - The range of movement of a joint. Exercises which put each joint through its full range.

Reflex (Arc) - A reflex is an involuntary response to a stimulation. Example: the leg jerks when the knee is struck. A reflex arc is a chain of nerves which carry impulses along a pathway from a sensory nerve to the muscle or gland which automatically reactes.

Reflux - Backward flow of urine up ureter towards kidney instead of out through the urethra.

Rehabilitation - The processes of treatment and education that lead a disabled person to attain maximum function, a sense of well-being, and a personally satisfying level of independence.

Respiratory - Refers to the organs and processes of breathing.

Sacral - The section of the spine adjacent to the hips; the lower back. The spinal nerves extending from the lower back.

Sacral Sparing - An incomplete spinal injury in which the sacral nerves and their connections with the brain remain intact, allowing for sensation and sometimes control of the bowel, bladder and genitals.

Scoliosis - An abnormal "S" curve in the spine to one side or the other.

Secretions - Fluids produced by the body such as mucus.

Sensation - A feeling or awareness of conditions inside or outside of the body, based on information taken by sensory nerves to the brain. Examples are: hot or cold, pressure, pain, sight, sound, etc.

Sensory - Refers to the nerves which conduct information from various parts of the body to the brain creating sensations.

Spasticity/Spasm - Involuntary sudden contraction of a muscle.

Spastic Bowel - The muscles of the bowel and anus are contracted (tight) and peristalsis is normal. Occurs in Upper Motor Neuron injuries.

Sphincter - A valve-like circular muscle which serves to hold an opening closed. Example: anal sphincter.

Spinal Shock - Cessation of most or all nervous activity below level of the injury, including reflexes. Occurs after SCI and may take one to several weeks to resolve.

Thoracic - Section of the spine in the chest region. The spinal nerves associated with these vertebrae.

Thrombophlebitis - Inflammation of a vein with formation of a clot within the vein.

Ulcer - An open sore. A gastric ulcer is a sore on the lining of the stomach.

Upper Motor Neuron - Part of the chain of nerves which carries movement messages from the brain to the muscles. The upper motor neurons extend from the brain to a point in the spinal cord where they link up with lower moter neurons. Damage to the upper moter neuron leaves some reflexes intact; tone will remain in the affected muscles, but there will be no voluntary movement.

Urinary - Refers to the organs and processes which produce urine.

Urine - Fluid produced by the kidneys containing water and waste products to be eliminated from the body. Stored in the bladder, urine is expelled at intervals in the process called urination.

Urodynamic Studies - A special x-ray test which allows the doctor to see how your bladder is working, how much urine it can hold, and whether or not there is any reflux of urine into the kidneys.

Urologist - A doctor who specializes in treating disorders of the kidneys, ureters and bladder.

Venous Stasis - Pooling of blood in the veins, resulting from immobility.

Vertebra - One of the chain of bones that makes up the spinal column.

Weight Shift - A technique for relieving pressure on pressure points by shifting your weight at intervals. An important aspect of skin care for prevention of sores.